Involving children and young people in healthcare

A Planning Tool

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For further information about PPI please see the NHS Centre for Involvement website www.nhscentreforinvolvement.nhs.uk and the Department of Health PPE pages www.dh.gov.uk/ppe

For further information about Action for Sick Children see www.actionforsickchildren.org

This guide has been written with providers of healthcare services for children and young people as its prime audience. Commissioners will however find the guide useful in enabling them to understand the types of PPI that service providers could and should be providing.
The National Service Framework for Children, Young People and Maternity Services changed the focus of the way health and social care is delivered for children and young people but also the way in which we must involve them in the decision-making process. This was strongly supported by Every Child Matters (2003) which sets out the proposition that everyone working with children and young people should have a common set of skills and knowledge. One of these common core skills is that we should have effective communication and engagement with children and young people.

This planning tool aims to support people working with children and young people, in the healthcare sector, whether acute or primary care, to help you in the process of engaging with children and young people.

As well as the powerful arguments for better engagement set out in the National Service Framework and Every Child Matters the review of the NHS completed by Lord Darzi (2008) identified children and young people as a priority group. Each strategic health authority convened groups of local clinicians and other to consider the evidence for improved models of care across eight broad priority pathways, one of which is Children and Young People. The pathway groups were charged with developing plans to address how to design and deliver the best quality of care for patients based on the latest clinical evidence and the views and experiences of patients.

There have, of course, been other policy imperatives as well, some of which are discussed further within this tool. Bringing all of this together, over the last few years we have seen a real push towards improving health and social care services for children and young people with particular emphasis on looking at their holistic needs. There is an increasing recognition of the need to enable greater consistency of services and greater choice through better commissioning and better co-ordination of services including health, social care, education, sport and leisure, policing, early years provision, fostering and adoption and so on.

Alongside these service changes a parallel set of reforms have been taking place across all service user groups, giving patients, carers and the public citizen a more direct say in shaping the organisation and delivery of public services, including health. Enabling greater engagement and participation does present particular challenges for those commissioning and delivering services for children and young people. We have come to realise at last that if we want to know what children and young people think we must ask them. We can not assume that as adults we can ever see things from the perspective of a child or young person and nor should we expect parents and other carers to be able to give an accurate proxy view of
a child. This is not to say that they do not also hold views that we should also listen to, but rather that the two viewpoints are not interchangeable. What this means is that we have to put in place sustainable and robust structures and systems to engage with the children and young people who use, or potentially will use, our services.

In 2006, Action for Sick Children applied for funding from the Department of Health (England) to review whether children and young people were participating in healthcare service planning and delivery, and assesses what best practice, if any, was taking place, with the idea that this information would be nationally shared. It was successful in its bid and a number of pieces of work were undertaken. This included a literature review and consultation with 15 NHS Trusts in England (See Action for Children, 2006; Coad & Houston 2007; Coad et al, 2008). This was in addition to the previous work that ASC had commissioned which led to a booklet being produced on involving children and young people in service planning and delivery (Ed. Smallman 2005), giving examples of good practice.

Whilst there were many areas that were developing a culture of participation and engagement with children, young people and their families, it was also apparent from this work that there was still some way to go for this to be embedded into NHS organisations and their practice. One area which caused the group concern was that whilst there were solid examples, which could be drawn from education and social care settings, there was less evidence from the health service. Thus the idea for this planning tool was born.

Representatives of Action for Sick Children and the NHS Centre for Involvement met to identify how they may collaborate to support their mutually inclusive agendas. Following on, this tool which explicitly looks at practical aspects of involving children and young people in healthcare came about. Further discussion took place and an expert panel was established. The aim of the panel was to improve the ways in which children and young people are involved in healthcare with an ultimate aim of improving experiences. This document represents the outcomes of that work.

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Executive Summary


• Funding obtained by Action for Sick Children (ASC), from the Department of Health (England) enabled a review of healthcare to determine if this was actually happening. The results of this led to a partnership between ASC and the NHS Centre for Involvement. An expert panel was convened.

• The group had the remit to develop a planning tool for healthcare providers to aid them in the process of engaging with children and young people in healthcare services planning and delivery developing.

• The tool was organised around a wheel of involvement made up of eight spokes which together make up the end-to-end process of children and young people’s involvement.

• We have devised a fictitious Case study throughout as an example to help illustrate each part of the process.

• The process starts by getting organisations to undertake an audit of existing children and young people’s activity. Good Patient and Public Involvement should comprise a balance of individual and group activity; proactive and reactive activity; retrospective and real-time activity; and direct and indirect activity. A simple audit enables organisations/units to get a feel for the extent of activity and to identify gaps.

• When undertaking any engagement with children and young people it is important to ask why you are involving them and what you are seeking to do through involvement and then set clear aims and goals that can be monitored and measured.

• Before embarking on any specific children and young people activity organisations should make sure that they identify what information they already have about that activity. In this way activity can be planned sensibly and appropriately.

• The process of participation and involvement, (children and young people being no exception), does entail the use of resources both in terms of money and people-time. Costs should be identified when planning activity so that this does not ‘fail’ because of a lack of resources.
• Identifying who needs to be involved in the children and young people activity is dependent on the aims and goals. It might be appropriate to segment the target population into smaller groups by age, gender, location or other characteristics.

• The methods chosen for the children and young person activity should match the nature of the activity, the people you want to involve, the resources available and the aims and goals. A list of possible methods is provided within this tool and throughout we have fictitious exemplars. Evaluation is a key phase in the process wheel but is also the most challenging phase. Identifying the impact of involvement requires the use of a range of different outcome measures, including measures of children and young people’s experience which are not always simple to capture.

• Providing feedback to those who have been involved is the final phase of the wheel. The way in which organisations do this will influence how much trust and confidence children and young people have and will also influence how prepared they are to continue to be involved in the future.

• Celebrate! Undertaking involvement projects are daunting and hard work and so at the end of the project it is important to share your experiences and celebrate your success.
How to involve children and young people in healthcare

The previous literature review performed on behalf of Action for Sick Children found several practical guides, tool kits and accepted principles to involving children and young people (Coad & Houston, 2007). All stressed that children and young people have different preferences for participation. However, the reality of using these in healthcare setting and subsequent evaluation to date was limited.

Thus this planning tool will provide a means in which healthcare trusts can be supported in undertaking this role.

Who the Tool is for

The short answer to this is that it is for any organisation that provides healthcare services accessed by children and young people, the staff within those organisations and interested members of the public, including:

- Senior leaders including the Executive and Non-Executive teams of Trusts such as the Chief Executive and Directors/senior managers within organisations that provide healthcare services for children and young people.
- Clinicians and non-clinical staff working in settings providing healthcare services for children and young people.
- Those who manage and organise children and young people service provision, whether based in an NHS, for profit, non-profit or social enterprise.
- Directors with responsibility for service reconfiguration.
- Service users, carers and members of the public who have an interest in this area.
- Patient and Public Involvement (PPI) professionals i.e. those people that have a significant role in PPI across an organisation providing services for children and young people such as people working in the NHS in the Patient Advice and Liaison (PALS) service.
- PPI professionals i.e. those people that have a significant role in PPI across an organisation providing Mental Healthcare services such as people working in the NHS in the Patient Advice and Liaison (PALS) service.
- Service improvement leads.
- Patient and Public Involvement leads in Strategic Health Authorities (SHAs) in their role to quality assure community engagement.
- Voluntary organisations.
- Community groups.
What the Tool is for

This unique aspect of this planning tool is that it aims to help you to plan the assessment, design, delivery and evaluation of the participation and involvement of children and young people in the healthcare settings that you work. It thus aims to meet the national and local imperatives around Patient and Public Involvement in order to:

- Help the healthcare provider make better, more responsive decisions about services for children and young people that have taken account of the views and preferences of local people, groups and communities.
- Clarify the existing involvement and consultation requirements within the children and young people’s healthcare system.
- Identify ways to make involvement and engagement processes more efficient and effective in healthcare services for children and young people.
- Show how the NHS and healthcare organisations should approach involvement and consultation work in healthcare.
Part 1

How to use the Tool

To get the most from this tool, each organisation that provides healthcare services for children and young people should make an honest and robust assessment of where it stands, in relation to:

- The effectiveness of recent and current involvement and consultation activity around care provision for children and young people – including work with staff.

- Plans for ongoing work to build a system of involvement and consultation that is integrated throughout each organisation that makes up the children and young people’s healthcare system.

In Part 2 of the Tool, we suggest ways to help organisations get started on this assessment. We feel that this is the right time for you and your organisation to take stock of what you are doing in terms of children and young people’s involvement so that you can plan and prioritise effectively and reap the key benefits of good involvement. In order to help you we have devised a fictitious Case study throughout as an example to help illustrate each part of the process.

We are including a checklist in order to help you do this (Appendix 1).

After undertaking a baseline assessment each organisation should feel one of the following:

- Well prepared and in a climate of positive public confidence. For those in this category this tool will act as an advisory checklist.

- That children and young people’s positive involvement is ongoing but there still are gaps. In this case the tool will help you plan further work.

- That very little involvement of children and young people has taken place or that participation has not influenced service planning and delivery. This tool will provide comprehensive and up to date advice based on evidence and practice. It will also provide links to relevant statutory guidance and give some tools to help plan and undertake robust engagement and consultation processes.
Patient and Public Involvement – driving forwards

Building any involvement system for developing, monitoring and evaluating healthcare services is complicated and takes time. Involvement of children and young people is even more challenging because of issues of age, understanding, consent, access and availability, interest and so on. In this section we present involvement as a set of different phases and processes illustrated with examples from children and young people’s healthcare. We have called this the Patient and Public Involvement ‘wheel’. It is based on the Patient and Public Involvement Cycle developed by Tritter et al (2003) and adapted from work the NHS Centre for Involvement undertook in the field of urgent care.

If these areas are fully acknowledged and addressed and they have a positive experience from the involvement process then they are more likely to be fully engaged.

The different components within the wheel relate to one another and each phase of the process builds on previous work and leads to the next phase. You and your organisation can start your involvement journey at any point on the wheel although there are clearly some phases that are more obvious starting points than others depending on the nature of the involvement activity.

We have kept the discussions of the various sections of the wheel deliberately brief but have sign-posted different sources of information so that you can follow up issues of particular interest. Before we move on to discuss the different components we wanted to start by briefly looking at what we mean by consultation, involvement, engagement and participation.
Consultation to participation
(See also Glossary on page 19)

Boyden and Ennew (1997) suggest that there are two interpretations of user involvement. It can simply mean taking part, being present, being involved or consulted, or alternatively it can denote a transfer of power so that a participant’s views have an influence on decisions and knowing that one’s actions and views are going to make a difference and may be acted upon. Consultation has been defined as ‘a process which requires the commitment to take on board children and young people’s views and present detailed information back to them’ (Treseder, 1997). Participation and engagement, on the other hand, arguably is a more active and empowering experience.

Case study

We have also devised the fictitious Case study below and will use this as an example to help illustrate each section of the process.

Scenario example:

You have been assigned a project to redecorate your department/unit and have been given a small budget and six months to complete the work.

You are very keen to invite children and young people in the project but would like to map and evaluate their involvement from start to finish.

You decide to use the involvement wheel to help you.

The case study is an aid to help you through the process, you may however have other examples you could use.
How to involve children and young people in healthcare

Phase 1
Mapping existing activity

All organisations need to know what Patient and Public Involvement (PPI) activity is going on within the services they provide. This must include the involvement of children and young people. Organisations need to be able to provide evidence of PPI activity and its impact when they are bidding for contracts, taking part in contract reviews, demonstrating that targets and standards have been met and so on. For providers of health services for children and young people there is an expectation that organisations will regularly audit patient experience, including PPI activity.

Undertaking an audit of involvement activity will give you a good starting point for moving forwards with new activity, will help to embed existing good practice and identify existing capacity within your organisation. Auditing activity does not need to be complex although using a short standardised form fed back to a coordinator can help generate a coherent database systematically and will make it easier to sort and share evidence and examples (see Appendix I).

As a starting point, we are including a basic audit tool for you to use to undertake an initial assessment (Appendix 1). The topics included are key areas which are considered important to children and young people, however there are other audit tools available which you may choose to use instead or adapt to your own needs. There also are a range of available tools that can be utilised such the checklist from Patient Insight: harnessing the power of public opinion www.drfosterintelligence.co.uk/newsPublications/localDocuments/Patient_Insight.pdf
When auditing activity it is useful to remember that PPI covers a **spectrum** of activity including:

- participation in decisions about treatment and care;
- involvement in service development e.g. planning and design of services, commissioning;
- evaluation of services;
- involvement in teaching; and
- involvement in research.

The audit tool enclosed is an example of mapping a whole service but can be adapted for use on a specific or smaller project (Appendix I). Below we have used the Case study to identify some sources of information that should be readily available to support your initial and ongoing audit:

**Case study: Do a mapping!**

You should map what you are doing already in your department/unit in order to assess what information you already have which can contribute to your project. For instance, this could include information from:

- patient and staff survey data;
- data from complaints, concerns and compliments;
- inspection data from e.g. Care Quality Commission, Internal Audit;
- clinical audit data;
- committee membership i.e. children and young people representation with equal rights;
- feedback through website;
- patient satisfaction/patient experience data (locally gathered – paper versions and electronic handsets);
- comment cards (from children, young people and staff);
- recent consultations;
- expert patients involved in teaching staff; and
- children and young people involved in any research activity.

**Make a list** of your strengths and gaps.

**Make a plan.** From here you can make a plan for building on the strengths and filling the gaps.

**Scenario example**

Map what information you already have on the department which relates to the décor.

**One final point** – it really is worth keeping the audit ‘live’ and adding to it on an ongoing basis. It is much easier to update your lists of activities regularly than to have to keep starting from fresh and you will find these lists enormously useful for all sorts of purposes. It is however suggested that you incorporate a review date in your audit process.
Phase 2
Aims and goals

The next section of the Involvement wheel focuses on clearly identifying the aims and goals of each involvement activity.

Key questions you need to consider in this phase are:

• Why are you involving children and young people?

• What do you want to change, evaluate or develop?

Identifying why you are involving children and young people is absolutely fundamental to becoming a good involvement organisation. We have seen examples in our work across the country where children and young people have been encouraged to volunteer to be part of a PPI group or system, but they are not then approached to ‘do’ or ‘be’ anything and so, not surprisingly, become disengaged. We have also heard anecdotally of situations where children and young people have taken part in a consultation but found out later that the decision had already been made and so their input was worthless.

In both cases, the emphasis has been upon recruiting children and young people to be involved without giving thought to why. If, for example, government policy or financial constraints means that there is only one choice then do not involve children and young people on the pretext that there are different options for proceeding. It may be appropriate to consider a minimal change as one possible option.
Case study: Think tank!

Scenario example

Think and talk about the following with other staff:

- Why are you and your organisation involving children and young people? E.g. we want to know what the experience of patients has been in x; we want to know what people’s expectations are about y.
- What do you want to change, evaluate or develop?

We mentioned in Phase 1 that there is a broad range or spectrum of reasons why you involve children and young people from individual participation in treatment decisions to involvement in research. When answering this second question, think about where the involvement fits into the spectrum of activity (page 14) and consider two further distinctions to help define your aims and goals:

- Is this a continuous and proactive involvement activity such as including children and young people on key decision making groups within your organisation or setting up a reference panel to support ongoing decisions about service redesign?
- Is this a one-off project that requires children and young peoples input for a limited period of time?
Phase 3
**Identifying existing information**

The third section of the Involvement wheel is about identifying existing information relating to the activity in which you are seeking to involve children and young people. This is an essential part of the involvement process in order to:

- avoid undertaking activities that are already taking place elsewhere;
- enter into an activity or process with the best available evidence to hand;
- identify what sorts of activities have been successful in the past; and
- identify the members of staff that have experience and expertise in involvement.

For instance a good starting point is to make sure you are aware of legal and policy information that relate to the activity, large scale relevant research and any relevant public health or demographic data.

We refer again to the spectrum of involvement. If your involvement activity is about, for example, the evaluation of services then you would want to ensure that you have all the information available about that service such as:

- complaints, concerns and compliments data concerning that service;
- any incidents relating to that service;
- any central or local policy drivers relating to that area;
- any audit data relating to that area; and
- any public health data relating to that area.

You will then be in a position to build an evidence-based evaluation process designed around what you now know are the issues you need to concentrate on.
Case study: Map what existing information there is

This includes:

- existing literature and evidence;
- local and national policy;
- local and national contacts;
- any public health data; and
- any audit data in the public domain about involvement.

Scenario example

What work has already been undertaken elsewhere to involve children and young people in contributing to designing/redecorating a department either within your Unit or nationally/internationally?
Involvement costs money. A dedicated and realistic budget is crucial to support involvement activities across an organisation. The last thing you want is to run out of funds part way through an activity. The fourth spoke of the Involvement wheel relates to identifying resource requirements and you need to consider including:

- staff time;
- fitting the methods to the resources;
- reimbursement of people’s expenses/reward and recognition for their time; and
- support for staff and people you involve.

**Staff leadership**

For any involvement of children and young people to be successful you need to identify suitable resources, this does not just mean finance or staff time but you are also looking for individuals who have the skills to take this forward. By doing that effectively, you will actually save on time and resources. No one person needs to do everything but it is suggested that you chose an individual to lead the project in order to make sure it remains on track.

When you are planning your activity you need to make sure that all members of staff involved are clear about what they must do and deliver, by when and in what form. Therefore identification of a leader to take forward the specific work will ensure that these things are factored into the plan. This will include how much time the project/activity is likely to cost and how much time it will take.

Resources are about more than money and time. The staff, patients and the public, undertaking or affected by involvement work, need to be supported and may need training. This is particularly the case where patients or members of the public are engaged in ongoing activity within an organisation. Again the leader of the project can identify what training, if any needs to be undertaken and factored into both the plan and the costings.
Fitting the method to the resource

We highlight some examples of methods of involvement on page 28. In an ideal world the method would be chosen because it is the best way of involving children and young people. However, most organisations have limited resources and methods should be chosen that are consistent with the available budget and expertise. The case study highlights some questions that you may like to consider.

Case study: Think tank!

Scenario example

Think about your existing department and this project:

- What is the designated budget for this project?
- Can you seek additional support?
- Can you piggy back your activity onto another project?
- What are the timescales for the project?
- What is your personal timescale for the project?

Reimbursement of expenses/payment

Organisations must make sure that children and young people who get involved in your activities are not disadvantaged financially and should make provision to at least pay out-of-pocket expenses at the event; expecting a child, young person or their family to wait weeks to be reimbursed for a train or taxi fare is not acceptable. An organisational policy on reimbursement for PPI helps to demonstrate that participants are valued for the time they give to involvement work (see Reward and Recognition, Department of Health, 2006). The Volunteering England website contains excellent information about volunteer expenses on http://volunteering.org.uk/ Resources/information/ on-lineinformationsheets/
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Whatever you do you should try to ensure that, as far as it is possible, it does not cost the children, young people or their families to get involved. You will need to consider what form of reimbursement is suitable for the child or young person.

We have taken views from INVOLVE; the Royal College of Nursing guidance (2006) and Department of Health guidance (2006), who suggest that you should try to reimburse travel as a minimum agreement of involvement and aim to recognise users’ contribution. This may include parents if they have to transport their children. Regular feedback and acknowledgement are an essential part of reward. In terms of children and young people, some other alternatives to payment such as reward in the form of a gift token, a letter or certificate of recognition and/or a group ‘treat’ such as a party have been organised. Rewards may have implications for users who receive benefits and for the organisations giving the reward. In both cases, implications should be explored prior to service users agreeing to take part.

Useful references to advise you further include:

Available from:
Email: dhprolog.uk.com
Telephone: 08701 555 455
Web: www.dh.gov.uk/assetRoot/04/13/85/24/04138524.pdf

Royal College of Nursing (RCN) Guidance on User Involvement in Research by Nurses (2007).

INVOLVE www.invo.org.uk/pdfs/Payment_Guidefinal240806.pdf
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Phase 5
Identifying people

In the first instance those you wish to involve are likely to be in one or more of the following categories as highlighted in the case study below.

Case study: Think tank!

Scenario example

Make list and contact those people who are the likely people who can help you?

- Patients – children and young people.
- Parents or carers.
- Potential service users – children and young people.
- Health professional staff / Multi disciplinary team.
- What staff have skills of consultation with children and young people?
- The general public.
- Members of local voluntary and community organisations.
- Commissioners of services.
- Service providers.
- Contacts you know that may have skills to help!
You can then segment these groups into smaller sub-sets by characteristics such as age, gender, known illness and so on. Remember however, when recruiting adults to work on the project you follow the principles of safeguarding children and ensure the child and young persons safety at all times.

You will then need to decide on ‘how many’ of each category or groups you will involve. It is useful to consider phases 5 and 6 of the Involvement wheel together as the involvement method(s) selected need to be appropriate for the children and people you are intending to involve. The methods will also determine the number of children and young people you will need to involve. For example, a questionnaire can reach a far larger number of participants than one-to-one interviews, but to be relevant has to have a large number of responses.

Recruitment of Children and Young People
The recruitment of children and young people in the involvement process will depend on individual organisations and the purpose for which that organisation wants to seek their views. In some cases you may access the children, young people and their parents who usually use the service or department. In other situations it may be more pertinent to contact the relevant support groups or local groups which have access to children and young people.

Consent
In some instances, it may be necessary to obtain consent to involve the child or young person. This may come from the child, young person or parent/carer depending on the circumstances. Your Research and Development team may be able to help you with this so seek their advice on suitable consent forms and the process for obtaining consent. Alternatively Action for Sick Children produce advice on consent called ‘Consenting to treatment for children and young People’ which can be obtained from their website; www.actionforsickchildren.org

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Phase 6
Identifying methods

Methods of involvement
In Appendix 2 we have included a ‘top tips list’ of methods of involvement (Coad, 2007. Contact Jane Coad at Centre for Child and Adolescent Health, Bristol www.bristol.ac.uk/ccah/). As we have stressed before, the involvement process involves an integrated series of phases that build upon each other. Section six of the Involvement wheel relates to your choice of method or methods.

Case study: Think tank!
• What is the best method (s) that you feel would fit the brief of the project?
• In answering this question you will need to consider all of those questions identified in earlier phases:
  • Why are you involving children and people?
  • What are your aims and goals?
  • What have you done before in this area? What has worked and what has not worked?
  • What resources (money, people, and time) do you have at your disposal?
  • Which segments of the community do you need to involve?

Scenario example
To seek views of children and young people in planning the new décor of the department you may choose to undertake a focus group. You may consider using art based methods for young children. (Appendix II)

What we are trying to stress is that the method or methods must fit the activity. For example, questionnaires and focus groups are fairly traditional methods of collecting information in the context of service evaluation and development. There are also other methods such as workshops and partnership forums that can be used, as well as information technology-based methods such as blogging and SMS-feedback.
Workshops or focus groups are examples that offer a useful method of bringing children and young people from different backgrounds together for problem solving and can be used at various stages of service development.

Partnership forums on the other hand offer the opportunity of involving users in a more formal, longer-term capacity. Partnership forums take a number of different forms. They can be made up of mixed groups, including professionals and users, and can include other stakeholders such as members of the public. They generally raise the profile of user perspectives within organisations and can have formal links with NHS structures as well as acting informally in an advisory capacity.

SMS messaging and blogging provide a means of participation which children and young people are often very familiar. Not only does it provide a familiar medium but it can be enabling children and young people who may not wish to be identified and provide feedback about their experience of services. Two challenges you must consider if you chose this method are that you will need well developed IT systems and a clear governance strategy in place to protect both participants and staff.

There are many times when a single method of involvement will not be sufficient and the nature of activity requires a mix of methods in order to maximise involvement. This is more likely to be the case when a system wide engagement activity is planned.
Phase 7  
Evaluation

The seventh section of the Involvement wheel concerns working out how you will evaluate the children’s and young people’s involvement within your organisation. Illustrating the different involvement phases within a wheel emphasises very clearly that user involvement is a continuous process rather than a one-off activity. Evaluation is a crucial aspect of involving children and young people, and it identifies the impact of the involvement, some of which is only apparent long after the actual involvement exercise is completed.

A strategy for evaluation must reflect the previous phases of the wheel. Just as you chose a method of involvement that is fit for purpose so you must choose an evaluation process that reflects why you are involving children and young people (who), what the focus is (what) and using which methods (how).

Evaluation is absolutely fundamental to the other phases within the wheel. After you have planned your activity and implemented it you must evaluate it to see if it has had an impact and whether that impact is an improvement. This not only helps you in your current work but will inform future activity.

Case study: Think tank!
- How well did the project go?
- How involved were the children and young people?
- What were the successes?
- What could you have done better?
- What impact did you have on services?
- Did the project come within budget and within time?

Scenario example
What do the children and young people think of the new décor?
The final section in the Involvement wheel focuses on developing appropriate ways of providing feedback about involvement activity. This should take place at two levels:

- Generic, routine and regular reporting.
- Targeted feedback.

**Routine feedback**

We mentioned in the first part of the Tool that there are benefits of involving children and young people which relate to meeting quality requirements, standards, and targets and so on. Developing a system of regular reporting about this to your organisation’s Board (or equivalent body) provides evidence of the types and intensity of activity and can help provide a basis for informed decision-making. This demonstrates that involvement of children and young people is being considered at the highest levels within the organisation. Board papers of NHS organisations and most equivalent papers from independent sector organisations will often be made public on websites and this permits members of the public to get feedback about their own and others involvement in the organisation if they know where to go. It is also good practice for senior managers to take time to thank those that have made valued contributions to the organisation either publicly at Board meetings as well as personally and periodically in writing.

Other forms of routine feedback can be linked to how information is gathered. For example, in a clinic you can have a comment box, specifically for children and young people, and then regularly review comments and respond to them by placing the organisation’s response above or near to the comment box. You might also consider developing ways to respond through your website, for example.

**Specific feedback**

Specific feedback to participants who have, for example, contributed to a consultation or who have participated in a focus group needs to fit the purpose of the consultation or activity. Ideally you should make sure that if children and young people have made the effort to write to you with their views on a personal level you should make the effort to reciprocate and respond personally.
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Case study: Think tank!

Who do you need to feed back to?

Scenario example

Feed back to the Board on the outcome of the project process and outcome.

Share and celebrate

It is important to share your experiences as others will face the same challenges you have and so can learn from you. This can be done by writing an article, presenting at a conference or simply sharing it with the trust through a newsletter.

Finally it is important to celebrate. How you do this is entirely up to you, you may even have a party! Take time to celebrate the success of the project.
Children and young people

For the purpose of the toolkit, the term children and young people is used to refer to those under the age of 18 years. This is thereby consistent with the definition used by the United Nations (1989). Where it is necessary to refer to specific age-groups, the following terms are used:

- Infants: less than 2 years
- Children: 2-10 yrs
- Young People: 11-18 years

Health

In accordance with WHO (1980) ‘health’ is defined in its broadest sense and is taken to be ‘a state of complete physical, psychological and social well-being and not simply the absence of disease or infirmity’. Health services are therefore defined as those services that address these aspects of well-being.

Participation

Participation and engagement are more active and empowering experiences where users are collaborated with. Users may also plan and have ownership of the management of the project.

Consultation

Consultation is a process which may be one off or ongoing but takes on board children and young people’s views and present detailed information back to them.
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http://www.participationworks.org.uk/resources?filter1=HowtoGuide

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Signposts Two. Putting public and patient involvement into practice in Wales.
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Acknowledgements

We would like to thank the members of the Expert Panel for their contribution to this document.

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Katie Barnes
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Stacy Curzon
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Fran Farrar
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The Children’s Society
Faith Gibson
University College, London
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Birmingham Children’s Hospital Foundation Trust
Angela Reynolds
Participation Works

A special thanks goes to Professor Jonathan Tritter, University of Warwick, who co-wrote the Urgent Care Guide and upon whose framework this is based.
## Audit Tool

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes /No</th>
<th>Proposed Action</th>
<th>Action</th>
<th>Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does your Trust have a dedicated Children and Young People Advisory Group or Council?</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Are you involving children and young people directly in any part of the Trust agenda?</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Is there a strategy for involving children and young people?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have a designated lead person responsible for involving children and young people in the Trust activity?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have resources allocated for the prime focus of involving children and young people in the Trust activity?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much time do you allocate for the involvement of children and young people</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 1

### Audit Tool

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes /No</th>
<th>Proposed Action</th>
<th>Action</th>
<th>Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there policies and procedures within the Trust to support involving children and young people?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If you do involve children and young people in the Trust’s activity is it a) a one off activity; b) or a continuum?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you work with agencies/external groups to involve children and young people in the Trust activity?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have your staff the skills to involve children and young people in Trust activity?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you offer training for staff in involving children and young people?</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
### Methods of Involving Children and Young People

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Key Attributes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Publications, media releases and displays</td>
<td>Written with no requirement for dialogue, but can provide information on how consumers can participate.</td>
</tr>
<tr>
<td>Patient charters/constitutions</td>
<td>Written statements setting out what patients and customers should expect. These should specify service conditions and provide pathways for complaint and possibly redress for consumers.</td>
</tr>
<tr>
<td>Use of art in involvement</td>
<td>Anything from large scale public art projects to small events. Can be used in conjunction with other methods and aims. Useful way of engaging with people who are reluctant to express views.</td>
</tr>
<tr>
<td>Use of theatre in involvement</td>
<td>Anything from large scale to small events. Useful way of triggering views through the use of scenarios and story telling.</td>
</tr>
<tr>
<td>Consumer friendly administrative procedures</td>
<td>Reviewing and reforming administrative communication with consumers to encourage Patient and Public involvement and partnerships for health.</td>
</tr>
<tr>
<td>Project groups</td>
<td>Instigated by organisations to advise on specific issues and / or to guide a project. Time limited. May be used to demonstrate the value of Patient and Public Involvement to key players.</td>
</tr>
<tr>
<td>Surveys (questionnaires)</td>
<td>Means of gathering information. Agenda set by organisations. Scope of information limited. Quantifiable, but you need to know what you want to ask and have an appropriate array of respondents.</td>
</tr>
<tr>
<td>In-depth patient interviews</td>
<td>Extended, semi-structured (usually) face to face interviews. Provides rich information from selected consumers. Useful as a follow up to surveys to explore particular issues and / or for specific population groups, but time consuming.</td>
</tr>
</tbody>
</table>
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<tr>
<td>Focus groups</td>
<td>A facilitated discussion with usually about 6-8 people for 30 minutes to 2 hours. People can be invited on basis of who they are and what they can contribute to discussion. Interactions among participants can help explore issues rapidly and in depth. Used for information collection focused on a specific issue (not for decision making) and can include various examples and props. Provides rich information, but may not be representative of all consumers.</td>
</tr>
<tr>
<td>Submissions</td>
<td>Oral and written presentation of views. Dialogue limited. Can attract consumers who are organised and in a position to put in a submission. Less articulate / literate, non-English speaking background and / or socially disadvantaged consumers may be excluded.</td>
</tr>
<tr>
<td>Delphi technique</td>
<td>Formal process using a series of mailed surveys to selected individuals. Used for building consensus across consumers with conflicting views. May be useful for particular groups of stakeholders on specific contentious issues, but relies on good literacy skills.</td>
</tr>
<tr>
<td>Nominal group techniques</td>
<td>Small group process for clarifying priorities. May be useful for consumer involvement in identifying priority issues, allocating scarce resources etc. However, does not allow for much in depth exploration of the issues.</td>
</tr>
<tr>
<td>Suggestion boxes</td>
<td>Easy to implement, but may be limited in obtaining useful feedback. May attract negative and unhelpful comment. Only for use in conjunction with other strategies. Responses limited to those with time and literacy skills.</td>
</tr>
<tr>
<td>Hotlines and phone-ins</td>
<td>Information gathering. Relies on publicity and the phone being attended. Works best with skilled staff or volunteers to answer. Attracts respondents fairly indiscriminately.</td>
</tr>
<tr>
<td>Text (SMS) messaging</td>
<td>Information gathering. Useful for getting feedback from young people.</td>
</tr>
</tbody>
</table>
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<th>Strategy</th>
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<tbody>
<tr>
<td>Complaints handling</td>
<td>Response to consumer feedback and complaints. Valuable resource because restricted to consumers who have identified possible area for service improvement. Requires staff understanding of the value of complaints. Not representative of patient experience or necessarily the worst service experience.</td>
</tr>
<tr>
<td>Responding to users initiatives</td>
<td>How your organisation/team responds to inquiries or requests initiated by consumers. Developing clear policies, processes and skills to be ‘response-able’.</td>
</tr>
<tr>
<td>Workshops</td>
<td>Working meeting usually of 8-12 consumers, possibly with providers, to share information and to develop a shared approach to a specified issue. Participants usually have been selected on the basis of particular skills, knowledge or experience. Requires informed participants.</td>
</tr>
<tr>
<td>Patient advocates / consultants</td>
<td>healthcare organisation employs person to consult with consumers and advocate on their behalf for service improvement.</td>
</tr>
<tr>
<td>Promotions and campaigns</td>
<td>Ways to get information out. Can be innovative and creative and can involve consumers, possibly through consultation in planning and partnerships in implementation.</td>
</tr>
<tr>
<td>Search conferences</td>
<td>Meeting of 30-50 invited people. Investigates a subject / issue in a planned manner. May use discussion paper as starter. Asks specific search question. Wide range of views canvassed. Answer(s) expected as outcome.</td>
</tr>
</tbody>
</table>
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<tr>
<th>Strategy</th>
<th>Key Attributes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distributing discussion papers</td>
<td>Written presentation of information for discussion. No dialogue involved unless structured. May, however, be used as precursor to public meetings or other discussion.</td>
</tr>
<tr>
<td>Public meetings and forums</td>
<td>Audiences usually over 20 people. Meeting structured to canvass views and / or debate an issue. Representatives, nominated by consumer groups / associations. Open to public.</td>
</tr>
<tr>
<td>Seminars and conferences</td>
<td>Instigated by organisations to explore ideas / issues. May cost and, therefore, be restricted to those who can pay. Audiences over 20 people. Format structured. Informal or spontaneous input may be restricted, tending to give providers / professionals more ‘air time’ than consumers / community.</td>
</tr>
<tr>
<td>User councils, panels and reference groups</td>
<td>Structure and role prescribed by organisation but should be negotiated and written down. Input to whole organisation based on advice from consumers. Need to ensure and support user representative links with appropriate constituency. Representatives need to have tenure long enough to learn to be useful, but not so long that they become part of organisation.</td>
</tr>
<tr>
<td>Policy round tables</td>
<td>Invitations to discuss policy items. Structured. Convened to advise on the development of specific policy and implications.</td>
</tr>
<tr>
<td>Stakeholder representatives on your committees</td>
<td>Informing, training and supporting, stakeholder representatives. Ensuring they have a relationship with their constituency. Negotiated and recorded roles and terms of reference for all members of the committees that they sit on. A medium to long term investment.</td>
</tr>
</tbody>
</table>
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<thead>
<tr>
<th>Strategy</th>
<th>Key Attributes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advisory committees</td>
<td>Usually up to about 15 members. Role is to provide input on an issue / subject on the basis of expertise about an issue / experience. Members can be appointed or elected. Usually limited terms.</td>
</tr>
<tr>
<td>Patient panels</td>
<td>Patients invited to focus on an area / issue. Usually structured.</td>
</tr>
<tr>
<td>Facilitating mutual support groups</td>
<td>Support to assist people, on their terms, about their issues. Groups can be consulted about service improvement. Clinicians can enter into partnership with groups as expert advisers.</td>
</tr>
<tr>
<td>Negotiation partnership</td>
<td>Patients, members of the public and providers work together to develop a written agreement as a basis for future process. May be part of consumer initiated participation. Requires clarity of objectives and good communication skills.</td>
</tr>
<tr>
<td>Networking</td>
<td>Informal relationship building with people who have common interests on goals. Will include building links to consumer organisations, advocacy groups etc.</td>
</tr>
<tr>
<td>Partnership of consumers and providers</td>
<td>Structured cyclical planning process with specified role for consumers in shared decision making with providers. Process and outcomes are a shared responsibility. Usually the result of years of development of Patient and Public Involvement and a strong consumer focus and culture in the organisation.</td>
</tr>
</tbody>
</table>
## Methods of Involving Children and Young People

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<thead>
<tr>
<th>Strategy</th>
<th>Key Attributes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Electronic logs (Blogging)</td>
<td>Patients and members of the public provide on-going continuous dialogue through web-site. May be consumer initiated. Informal relationship building with people with common interests or goals.</td>
</tr>
<tr>
<td>My Space</td>
<td>Patients and members of the public can provide feedback in an anonymous form. Useful to receive feedback about sensitive areas of service provision or where patients do not want to be identified because of the nature of their attendance e.g. sexual health and pregnancy conditions.</td>
</tr>
</tbody>
</table>
Appendix 3

Local Involvement Networks (LINks)

Information contained within this appendix is based on a series of fact sheets and guidance which can be found at www.nhscentreforinvolvement.nhs.uk

Local Involvement Networks will be set up in all Local Authority areas with social service responsibility by 1st October 2008. Once the LINk has been set up it (the LINk) will need to work in different ways with local Primary Care Trust commissioners and with health and social care providers of services.

The relationship between LINks and commissioners needs to include the following functions:

• Using the LINk as a vehicle to consult with local people about their experiences of health and social care.

• Using the LINk to consult with local people about proposed changes to the commissioning of health and social care.

• Responding to the LINk formally when they request information about a particular health (and social) care issue that has been generated by local people and adopted as a LINk issue.

• Responding to the LINk formally when they raise a particular health or social care issue.

Organisations that provide services and the LINk will need to develop a relationship to include the following functions:

• Providing information to the LINk about, for example, complaints and incidents and other data when they are requested to help inform the LINk about an emerging issue (an issue raised by a member of the public or an organisation).

• Complying with requests to enter and view premises (this might be when a LINk is exploring an issue to take to the commissioners and they are seeking additional observational data). Trained LINk members will be able to make unannounced visits as long as the visit does not disrupt services. There are also provisions about not using enter and view powers to go into any premises that constitutes a patient or individuals home (e.g. LINk can go into communal areas of a nursing home but not into private rooms; LINk can not go to the home of a Looked After Child).

• Using the LINk as a vehicle to demonstrate to commissioners that they have consulted on substantial proposed variations to service change. Good practice would indicate that Provider Services might want to consult routinely on any proposed variation (substantial or otherwise) that will have an impact on patients or the public.

• Using the LINk to involve local people in monitoring services.

• Using the LINk as a means to demonstrate to Care Quality Commission (the watchdog that has replaced the Healthcare Commission) that it has consulted and involved local people in monitoring and developing services.
Local Involvement Networks (LINks)

The host organisation is responsible for establishing the LINk and will look at how these functions will work in practice in consultation with commissioners and providers. Other things that the LINk must consider are:

- how it will decide if it should take on an issue that is brought to its attention;
- how it will log issues that are brought to its attention; and
- how it will raise these issues with providers and commissioners.

LINks will be expected to produce an annual report outlining its activity throughout the year and the host will need to provide accounts as to how it has allocated resources.

There is a great deal of further information about LINks available on the following sites:

www.nhscentreforinvolvement.nhs.uk
www.dh.gov.uk/patientpublicinvolvement