



National Children's  
Bureau

# Children, Young People and Health Participation

The National Children's Bureau supports children and young people to input into health policy and practice development. This document provides a summary of our learning from recent years, hearing what children and young people have told us is important to them.

## The culture of participation

Children and young people want engagement to be meaningful, useful and to:

**Be supported by practitioners with appropriate expertise and experience.** Collaboration between health organisations and participation professionals, with sufficient planning time, can help to ensure useful findings, safety, and smooth logistical arrangements. Children and young people value the role of empathetic adult professionals in listening to their opinions and helping them effect change; particularly when activities are supported by professionals familiar to them.

**Take a child-centred approach.** Participation opportunities need to take into account the inclusion of different ages (including very young children), those from different groups (e.g. looked after children) and with different needs (e.g. SEND, English as a second language). Young people can be trained and supported to take active roles as mentors, decision-makers, inspectors, spokespeople, or trainers to upskill health professionals.

**Inform actual change.** Listening to children and young people is part of delivering a good service and continuous improvement. The nature and limits of children and young people's influence need to be demonstrated clearly from the outset. It is important that they have the ability to provide feedback, including the option of giving it to individuals not involved in delivering their care, and are given reassurance that this feedback will be taken seriously and responded to.

## Right to information

Children and young people need information about their health and healthcare in ways that they can understand. This needs to happen throughout the patient journey. Information should be given in manageable quantities and revisited as relevant to their lives, since retaining lots of information over time can be difficult. Communication should be truthful, managing expectations and supporting children and young people's understanding of any health conditions, their choices, and relevant resource constraints. Involving children and young people in producing information should be a priority, increasing relevance, credibility, and accessibility. Information should be available in different formats. Digital technology could be greater used to support information, communication and participation. However, digital and paper resources cannot replace face-to-face contact and relationships with professionals, which are extremely important to children and young people.

## Involvement in personal healthcare decisions

Children and young people want:

- To be supported by health professionals who are confident in communicating directly with them and with whom they are able to build a relationship. They do not want to explain their experiences to, or hear the same information from, different doctors each time.
- Processes such as; privacy, consent, decision making, to be explained particularly where there are numerous individuals involved, e.g. if a child is looked after or is in transition between services.
- To choose how and to what extent their parents/carers are involved in their care and decision-making. Control over this includes being able to request time alone with the professional and being able to vary the involvement of parents/carers depending on the appointment or issue being discussed.
- Communication that is adapted to individuals' needs and capabilities.
- To understand why a particular course of action is being taken and to be involved in agreeing next steps.

## Access to high quality care

Like adults, children and young people have expectations about the quality of healthcare they will receive. For example, it is important that doctors and nurses are professional, give children confidence in their ability and undertake any treatment required swiftly. Services should be accessible when children and young people need them, rather than requiring them to reach a crisis point and/or an emergency admission.

## Right to complain

It is important to children and young people to have:

- Information and support to complain. The process needs to be simple and confidential and recognise their right to choose how others are involved.
- Assurance that complaints will be handled appropriately and effectively; with clear information provided about the outcome of the complaint.
- Greater confidence that complaints can lead to improvements and not adversely affect their care.
- Recognition of when things go wrong, even when there is no need to punish an individual.

## References

<http://www.ncb.org.uk/areas-of-activity/health-and-well-being/health-and-social-care-unit/strategic-partnership>

<http://www.getyourrights.org/>

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