



“C” is for Children’s and youth participation – who is involved?

A selected bibliography

Firstly, what is children’s and youth participation? It can be described as a right, a means to give “voice” and empower. Children’s participation is tied in with the process of learning about what children value and also with decision-making.

The thought and planning that go behind enabling children to participate become a means to build in change. Voiced ideas become the start of community services and projects and can be found across many initiatives in research, governance, [social care](#), development, environment, health and education. So numerous are the examples of participation today, that evaluation is gaining momentum and significance. Some questions asked are, what are the most valid and ethical ways to involve or engage children and “capture” their voices and opinions? How should this information be transformed into the design and build stage and finally what are the best methods to involve children in evaluation and feedback?

Value of participation and the future imperative

[Adults and children’s views of participation](#) are not necessarily the same and these understandings are developed along the way. Value can be placed on skills and support for participants and especially for children, to enable them to be fully involved. There is also value in participation when it is a process of mutual sharing, participants learn about the rights of others to have their “own voice”, they learn about collaboration. International organisations such as [UNICEF](#) look at increasing children and young people’s capabilities and promote opportunities to participate. With over 2.2 million people in the world under 18 and an estimated 87% living in poverty, participation is seen as a way to empower through development of skills. These skills may have positive impacts for the rest of children’s lives. It is becoming more widely recognised participation can lead to positive change for individuals, collectively and within systems.

How to define participation? In recent times it is easier to find more information about children’s and youth participation, though many meanings are used. Roger Hart, [in an article for UNICEF](#), describes how it can mean many things. He focuses on a model of genuine participation. This involves the right for children and youth to choose to participate in a program. Programs should be designed to maximize a child’s potential to participate and this will vary also because of a child’s developmental stage.

People turn to the United Nations Convention on the Rights of the Child, UNCRC and especially Articles 12 and 13. This involves the [right for children and young people](#) to have [expression and receive information](#) in matters concerning their lives and in accordance with their age and developmental stage.

Many examples of children's and youth participation [can be found in the United Kingdom](#) where legislation has been passed to continue the commitment made in UNCRC. There are community initiatives, services and research as well as frameworks for making progress such as models, [tools](#) and policies. Some government agencies make children's participation part of their daily work. Organisations such as [Save the Children](#) work towards improving the capacity of programs. There is information about children's participation that is written for children. Examples where community can track progress are informative and it is inspiring to see creativity at work.

One example comes from the UK organisation, Participation Works and their recent document, [Children's participation in decision-making: A children's views report](#). Authors refer to the UNCRC which broadly conceptualizes participation. "This term has evolved and is now widely used to describe ongoing processes, information-sharing and dialogue between children and adults based on mutual respect and in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes". Participation Work's definition looks beyond expression of ideas and includes change as an outcome:

"Participation is a process where someone influences decisions about their lives and this leads to change."

People who are not familiar with the concept may be asking the question why should adults listen to children? Are children just getting their own way? [Focus groups](#) concluded children are very aware of the unique perspective they offer. They are a different generation and are likely to have different problem solving skills and creative abilities.

Participation is a democratic process. Underlining any question about why adults should listen to children is the understanding that a democracy involves all citizens, so naturally children see themselves as part of their community and its processes. The Participation Works report concludes, adult-child inherent power differences were accepted by children although more likely to be negotiated as children grew older. What was not accepted was the low status adults placed on children's opinions and lack of explanation. Children were left feeling belittled and powerless regardless of the setting. Disabled children and refugee children were most likely to miss opportunities to raise concerns and therefore have them addressed.

At a policy and guideline level children and young people's rights are captured in the United Kingdom through the [Children's National Service Framework \(NSF\), 2004](#), and [Every Child Matters](#) (the Government decided this scheme would end). Here recognition is given to children being involved in the design, provision and evaluation of policies and services that affect them.

[Scotland's Commissioner for Children and Young People](#) is a resource rich place to visit, with publications on participation including *Closing the case: Detective Kit reports on what children told SCCYP about 'things to do'*.

[Participation of children in planning and assessment](#), by Play Wales and Save the Children Wales, includes play and participation, children as auditors, resources and links.

Participation in healthcare

What of children and young people's participation in healthcare and how does it work in these days of flat-lining budgets? An overview of definitions of participation and related levels of involvement within healthcare can be found in [Listening and responding? Children's participation in health care within England](#), 2005. Here, health policy developments in England are explored. One definition values participation as a meaningful process and not just an isolated event. Information is part of what makes it possible for a child to consent and take part. Parents and health professionals have a duty to provide children with information that they need to make informed choices. Younger children will need more support.

The Royal College of Paediatrics and Child Health have produced [Not Just a Phase – A guide to the participation of children and young people in health services](#). This overview document emphasises why it is important to continue the journey of participation, so children and young people have access to high quality child health services. *Not Just a Phase* is essentially written for paediatricians, child health nurses and service leaders. It is both informative and easy-to-read and really a great place to begin. There is information on the limited research evidence for children's participation. Future research should look at health outcomes and cost-effectiveness. Find out about safeguarding children, the potential participation has to reduce health inequalities, the role of youth workers in helping in the planning stage, service leaders and the culture of participation, methods of participation. Children participate in health service design, delivery of services, staff selection, governance of health services and research development. There is emphasis on participation contributing to quality of health services.

Research and children's participation are discussed by [Hart](#). His opinions gradually shifted to one where children are actively part of the process. Adults would not just create projects to research children, instead children would take part starting with the design and planning stage, from the "get-go".

Within healthcare, there is a need for greater collaboration and partnering between health professionals, families and patients. More children are both surviving longer and living with rare conditions and chronic disease, some are taking part in new treatments and clinical drug trials. Children need to know more about their illness, make decisions about treatment, be involved in self management and know healthcare providers have regard for confidentiality and ethics. Imelda Coyne [reviews the literature on participation](#) mainly published between 1993 and 2007 finding sick children's views were rarely consulted. More recently she wrote about children's involvement in decisions regarding their cancer treatment, [Interventions for promoting participation in shared decision-making for children with cancer](#) finding more research is required. Coyne et al. also wrote [Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences](#). This article published in European Journal of Oncology Nursing 2014, revealed children had minimal control over decisions about their care.

A New Zealand study that looked at adolescent participation and research methods entitled, [Obtaining adolescents' views about inpatient facilities using conjoint analysis](#). This draws on the effectiveness of conjoint analysis as a tool to capture "adolescents' voice". Researchers wanted to know what the consumers at Wellington hospital thought and reviewed their Adolescent model of care. Rather than continuing along with what had been done, they took

advantage of the opportunity of the preparation and building of a new hospital complex. The consumers, adolescent inpatients, had firm views about dedicated adolescent space and use of cell phones. Importantly, they showed that if “characteristics of services which are important can be ascertained and if economic considerations are added, the results can show how an optimal service can be provided within a definable resource.”

[Improving patient experience for children and young people](#): a report prepared by the Patient Experience Network for NHS England, is worth reading to find case studies and programmes designed for participation and with review of best practice. The best practice examples include children’s hospital initiatives with photos, overview and summaries of what was enhanced. One example came from Birmingham Children’s Hospital – Catering for children and young people (menu choices) with realistic images of the food and the patient is only able to view choices which are of relevance to them.

In an Australian context, [Models for engaging consumers and clinicians in policy: rapid reviews](#) produced by Health Issues Centre, described as an evidence check review by Sax Institute for the NSW Department of Health, 2008. The document identifies consumer and community participation tools at different levels: individual, program, organisation, government and community. “Many of the findings from the database search equated youth health engagement with employment or as members of a family”, pp 54-56.

[Doing it with us not for us](#) is the Victorian government’s policy on consumer, carer and community participation in the health care system. With demonstrated success, consumer participation is “an aid to improve health outcomes and the quality of health care; as an important democratic right; and as an accountability mechanism”.

The Paediatric Integrated Cancer Service (PICS) has [produced A Toolkit for consumer participation and engagement: paediatric oncology](#). In this document, you can find links to several documents prepared by health organizations within Australia concerned with improving health care systems by consumer participation. Some topics in the toolkit are what is consumer participation/patient centred care, why and how are consumers engaged, types of consumer involvement and evaluation methods and tools. Given the nature of family centred care, PICS defines consumers as children and adolescents with cancer, their parents/guardian, siblings and wider family members. Some reasons for engagement are outlined including “participation improves health outcomes” and makes “services more responsive to the needs of consumers”.

The Government of South Australia, [Office of the Guardian for Children and Young People](#) produced a bibliography in 2009 with links to participation resources including [NSW Commission for Children and Young People](#) who host [Your space](#) for children and young people and [participation resources](#). Other links include [Save the Children toolkit](#) and their free publication [Practice standards in children’s participation](#).

Participation in healthcare design

[Hart describes](#) how there are good reasons for architects and designers to include children in the design process. Child health facilities are a place where children are passive recipients of care and this is a time when life is difficult and often painful. Emphasis should be on children having control over the non-medical side of care. For a time hospital becomes home and children need to feel as though they have a meaningful space for themselves. Children participate in healthcare to create a better healing environment. AWCH has several books on this topic that may be available for loan. For example, [Improving the patient experience : Friendly healthcare environments](#), NHS England, which has a section on sense sensitive design and [Children's hospitals : the future of healing environments](#).

Katherine Bishop's thesis has much to explore regarding children and young people's perspective in the hospital environment. The thesis is entitled [From their perspectives: children and young people's experience of a paediatric hospital environment and its relationship to their feeling of wellbeing](#). Research was based on addressing gaps in current knowledge, two research questions were developed. "The first was concerned with describing children and young people's experience of the sociophysical environment of a paediatric hospital. The second question was concerned with understanding the role of the physical environment in children and young people's feeling of well-being in a hospital environment. In addressing these questions, the intention was to identify attributes within the hospital setting which collectively comprise a supportive environment for children and young people and which contribute to children and young people's feeling of well-being in a paediatric setting."

Bishop explores the strengths of participatory research for healthcare design and designing healthcare environments from the child's viewpoint. "Participatory research reveals children and young people's competence in their own lives. It also reveals the unique perspective they offer on their own experience. Through participatory research children and young people show that they are active shapers and managers of their own experience, even under difficult circumstances such as prolonged visits to hospital. They have an authority and a perspective on their experience that adults cannot have, and which designers, researchers and policy makers can engage with for the benefit of healthcare practices and services, and paediatric design".

Adults' assumptions are challenged. "In particular, the strengths of participatory research with children and young people for healthcare design lie in its capacity to challenge adult assumptions about children's lives and challenge adult's depictions of them." This will then challenge the way children and young people are accommodated within healthcare design.

"Grounding adults' understanding. Participatory research also has the capacity to ground adult understanding in the reality of children's experience rather than the imagined reality of children's experience. This also identifies the importance of completing research with children and young people in the contexts in which their experience is taking place." p 259

Design projects

The Commissioner for Children and Young people, Western Australia produced [Building space and places for young people](#). This document looks at child friendly cities and other systems of local governance and design of the built environment. Examples include

Djidi Djidi Aboriginal School, where school children actively influenced and contributed to the design, cultural values and artworks were incorporated. Colour photos show design elements and artworks in the school. Young children are under-represented in participation and design. This project focused on addressing this through inclusion of school children. The New Children's Hospital (NCH) replaces Princess Margaret Hospital for Children (PMH) in Perth. "To create a patient and family-centred paediatric health service, children, young people and families have been directly involved in the planning and design process of the new facility". They developed surveys, focus groups and forums mostly drawing on children and young adults who were PMH patients. There were focus groups with ethnic young people, focus groups with Aboriginal young people and focus groups and interviews with patients in the mental health inpatient unit.

The Center for Health Policy Design, Chicago produced [Understanding the role of hospital design on the psychological trauma of hospitalization of children : Report from the pilot study](#). This pilot study leads to greater understanding between hospital design and child and family stress. "It pilot measures of parental and child anxiety and stress during and after hospitalization, with the goal of developing a sound method for exploring the role of hospital design features in mitigating them. Once the methods are refined, they will be used in tandem to evaluate the design of the new Lurie Children's Hospital." One method used to capture children's experience of hospitalization was the photo activity. Children were asked to take photos and describe their reactions to their hospital room, the Brown Family Life Center (a medical-free play zone for inpatient children and adolescents) and their bedtime experience. They took photos of their most and least favourite things. Least favourite were most likely to be medical equipment (like IVs) in their rooms. Once in the play room children "were quite unlikely" to photograph medical equipment as a least favourite thing (even though they may have brought their IV). In the play room, art, activities and space were the most favourite things photographed. The photo/questionnaire approach provided "specific direction when exploring design elements more specifically for the full study". Adolescents mostly chose not to take photos instead taking part in the questionnaire. The participants valued the experiences of hospital life that made them feel normal.

The [Pebble project](#) also from Center for Health Policy Design is a unique project that enhances the design of projects to create a more efficient, effective healing environment. It is a dynamic collaborative and with the purpose of creating a ripple effect within the healthcare community, to increase knowledge and motivate and inspire change in other organizations.

Awards and recognition for better design

Building Better Healthcare, UK, promotes better design in many ways including award presentation. There is a category recognising patient experience. Judges voted on [Award for Best Collaborative Arts Project](#), Ferndene Children and Young Peoples Centre in Northumberland picked up the award in 2012.

Association for the Wellbeing of Children in Healthcare, AWCCH

In the past AWCCH librarians Eva Langley and Marion Steele compiled Design and decoration of the hospital environment for children and their families: a selected bibliography, 1983. More than thirty years later healthcare design is a hot topic and linked with children's healing and wellbeing.

When looking for information on participation today, there are many types of involvement, across many disciplines and with varying definitions. The databases capturing resources by indexing them, are not uniform in their use of terms. "Participation" may include anything from sports participation, inclusion of children with special needs, family law and children's participation in child custody involvement, clinical drug trials etc. Health databases use terms like "attitude to health", "choice behaviour", "consumer" and "advocacy". Researchers may use terms such as collaboration, consultation, engagement, involvement, "voice", child-friendly, patient and/or family centred care, measuring tool and research methods etc. For more resources see the AWCH Library catalogue, some are included under lists and [Children's participation in healthcare decisionmaking](#) and [Children's participation in healthcare design](#). The lack of uniformity is not surprising as this area continues to emerge. Attention now shifts towards participation measurement and evaluation methods, terms will evolve to capture this expanding area of the "research cycle" and there may be project "redesign".

Association for the Wellbeing of Children in Healthcare, AWCH has worked with Children's Hospitals Australasia, CHA for initiatives to emphasise children's participation in healthcare rights:

[Young people's healthcare rights, be in the know](#)

These rights were developed by young people at a conference held by Children's Hospitals Australasia and Association for the Wellbeing of Children in Healthcare.

[Charter on the Rights of Children and Young People in Healthcare Services in Australia](#)

CHA invited AWCH to partner with them on this project. The Charter of Rights, and a version in an appropriate format for children and young people form part of the project. The Charter is a package of 11 rights, point 7 of the rights for every child and young person is: to participate in decision-making, as appropriate to their capabilities, to make decisions about their care.

Just as the child-friendly versions are found at end of the Charter, this information ends on a child-friendly note. Where children are involved, there will be creativity, exuberance and qualities sometimes forgotten in adults such as play and fun. These qualities point to what is unique about children and emphasise why they participate.

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<http://library.awch.org.au>

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