

# Improving the Patient Experience of Children and Young People

## Introduction

A positive experience of treatment and care is rightly viewed as an important health outcome in itself. There is also evidence that a positive experience of treatment and care can result in improved clinical effectiveness and patient safety.<sup>1</sup>

Childhood and adolescence is a formative period in any person's life and therefore ensuring that children and young people, as well as their families and carers, have a positive patient experience is particularly important. Their experience of care today may determine their interactions with health services in the future, as well as shaping their wider life experiences. It can affect their long-term experience of illness, their wellness and their developing mind and body.

Yet delivering a positive experience for children and young people can be particularly complex. Not all children and young people are the same and the needs and capacity of a two year old will be very different from those of a 14 year old. Equally, two 15 year olds may have very different levels of maturity, requiring different approaches to healthcare. Some children and young people will have significant health needs requiring frequent interactions with health services, often over prolonged periods of time. There are also children and young people whose parents/carers may for numerous reasons (e.g. having physical/mental health issues or learning disabilities themselves, other siblings with complex needs) are not be able to advocate for their child, putting these children and young people at risk of poorer experiences of care. We also know that black and minority ethnic groups repeatedly report poorer experiences of care. Identifying that there are specific groups who are at risk of poorer experiences of care will help us tackle these challenges head on.

Services need to be designed in a way that reflects the changing needs and requirements of children depending on the different stages of their development. They also need to reflect the fact that children and young people may not have the same understanding of health issues as adults and communicate their concerns and views differently.

Improving the experience of children and young people is a priority for NHS England. For the first time, the experience of children and young people treated as inpatients will be measured in the National Children's Inpatient and Day Case Survey and a dedicated team is leading efforts to encourage commissioners to work with providers of health services to improve the experience of children and young people who require health services.<sup>2</sup>

Although recent efforts to improve patient experience have often focused on provider-led initiatives, it is important that commissioners also see patient experience as one of their core responsibilities. Put simply, patient pathways – which are determined by commissioners and often span many different providers – will do as much to determine whether or not an experience is positive as the quality of the provision that takes place along that pathway.

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<sup>1</sup> Cathal Doyle, A systematic review of evidence on the links between patient experience and clinical safety and effectiveness, 2013, accessible at <http://bmjopen.bmj.com/content/3/1/e001570.full.pdf+html>

<sup>2</sup> Care Quality Commission, National Children's and Young People's Inpatient and Day Case survey, materials are accessible at <http://www.nhssurveys.org/surveys/769>

This paper sets out the key issues identified by a group of charities who are experienced in supporting children, young people as well as their carers and families, which was convened by NHS England and supported by Incisive Health in November 2014. It is intended to help commissioners and others working to improve patient experience to identify and address the issues which are specific (or particularly relevant) to children and young people.

## Key themes

Much of what matters to adults will also matter to children and young people. The fundamentals of good care – and therefore a good quality experience of care – remain the same.

However, there are some issues which will be particularly important for children and young people:

1. **Communication:** *healthcare professionals should use age-appropriate language and engagement corresponding to the developmental stage of the child or young person*
2. **Involvement:** *the child or young person should be fully involved in decisions about their care with an ability to exercise choice and control*
3. **Mental health:** *recognising the impact that treatment and care can have on a person's mental health at a time when their personality is developing, services should ensure that mental health issues are identified and appropriate psychological support is offered to patients and carers across the pathway*
4. **Coordination:** *care should be coordinated, ensuring that needs do not fall between different organisations*
5. **Transition:** *particular focus should be given to supporting people as they move from children's to adult services as well as from specialist into general care and importantly the monitoring of ongoing engagement with adult services*
6. **Child and adolescent literacy:** *services for children and young people should understand children and young people. All commissioners should challenge themselves to consider how the services they are designing would look and feel to the person using them*

Below these issues are explored in more detail. This summary is not exhaustive but is intended to reflect the priorities that were identified by the charities at the meeting for improving the patient experience of their members.

### 1. Communication

- Healthcare professionals should tailor their communication to the developmental stage of the child or young person to ensure that they fully understand the condition, associated symptoms and the impact it is likely to have on their lives
- Using age-appropriate language and information material will help increase the child's/young person's confidence in raising any questions or concerns relating to their condition or treatment. Healthcare professionals should guide the child/young person through the information and assist in interpreting test results. The Patient Information Forum (PiF) Guide on Producing Health Information for Children and Young People is a helpful resource. Communication should be

centered around the patient's individual needs e.g. using condition-appropriate methods of communication for deaf or blind children and young people

- Engaging, involving and informing children and young people may require more time and this should be reflected in the diversity of the workforce, staffing ratios and work plans e.g. some Emergency Departments have introduced the role of a youth worker to support young people struggling with dependency, mental health, gang related violence issues
- Children and young people should know what to expect and how and where to seek help if they need it e.g. signposting information in school diary about local health services is an idea young people suggested, including who to turn to when they have concerns

## 2. Involvement

- Children and young people should be involved in decisions about their treatment wherever possible; care plans should be designed to take account of their wishes and preferences demonstrating choice and control. Children and young people should be treated as active partners in care rather than as passive recipients. Evidence of seeking information from children and young people about what matters to them is important, for example, University Hospital Southampton NHS Foundation Trust includes a sheet within its admission paperwork for the child or young person to illustrate or document the things that matter to them
- Involvement is critical in the delivery of care to individuals, but should also inform the design of wider services; the experience of one person should be used to inform a better experience for others

## 3. Mental health

- Ill health is challenging for everyone but, for children and young people, it can create a particular emotional burden. Childhood is a time of rapid emotional change and development and the psychological impact of ill health – and the treatment that goes with it – can be profound
- Mental and physical good health are interrelated and providing psychological/psychosocial and physical support should go hand in hand for children and young people
- It is important that mental health support is not limited to those with severe mental health needs, but is used to maintain and improve health, particularly including psychological support for those children and young people with chronic conditions

## 4. Coordination

- Many different organisations could be involved in delivering support to a young person. It is important that care should be provided by people with the appropriate expertise, but it is equally important that a person should not fall down the cracks between organisations in the process
- Children and young people are unlikely to have a detailed understanding of the health and care system, making effective coordination all the more important. Patients and their families should not have to be their own care coordinators. Instead they should have a familiar and trusted point of contact to whom they can turn when they need help and provide advocacy support either direct for/with the child and where necessary for the whole family unit
- The role of nurse specialists and special needs/disability health visitors in providing co-ordination, navigation, advocacy and ultimately better outcomes is consistently valued by children, young

people and families, as is facilitated peer support. If multiple consultants are involved in the provision of the child's/young person's care, a lead coordinating consultant should be appointed to ensure that all healthcare professionals work together in an integrated way

- Providers of children's services should be encouraged to participate in networks to join up care and ensure that different providers are working together in the interests of the people who use them

## 5. Transition

- A young person's care can be marked by significant transitions – from specialist to generalist care and from children's to adult services. These transitions can be unsettling and often come at a time when a person may be particularly vulnerable. Getting transitions right can be critical to maintaining trust in services and avoiding clinical disruption
- Transition should be timed to occur at a time when a person is ready for it, not to fit the convenience of the service. Appropriate assessment and support should be provided to help people make transitions. Programmes such as 'Ready, Steady, Go, Hello' delivered by the University Hospital Southampton NHS Foundation Trust have been recognised as supporting effective transition and should be implemented across the country
- Ongoing monitoring of retention of young adults within adult services is required to ensure young adults are not lost by the system as if this occurs, long term health challenges and complications will result

## 6. Child and adolescent literacy

- Caring for and supporting children and young people requires specific training and it is important that healthcare professionals are equipped with the necessary skills. Children and young people grow and change and the services that support them should reflect this
- Kindness and compassion can be particularly important for children and young people; services should seek to measure their performance on these through patient feedback mechanisms and through processes such as professional revalidation
- Particular focus should be given to helping children and young people feel comfortable in a caring environment, enabling them to carry on with every day activities in so far as is possible. This may mean focusing on the quality of food, providing Wi-Fi or access to toys and books
- Meeting the needs of a child means also supporting the needs of their family. An important example of this can be providing family accommodation to enable families to stay together during treatment, maintaining family life
- The UN Convention on the Rights of the Child must not only be respected but made real. These rights are not about simply technical compliance; commissioners and providers should instead work together to ensure that the spirit as well as the letter of every right is available to every person under the age of 18
- Young adults up to the age of 24 are particularly vulnerable as their brain continues to develop and an ongoing focus on their experiences of care is also required
- Further work is required by the Department of Health, Public Health England and NHS England to review the current 'You're Welcome standards' and consider the value of updating the standards and making them applicable across the age continuum of children and young people

## Conclusion

The NICE Patient Experience Quality Standard 15 currently does not address the experiences of children, young people and families/carers, which is a significant gap. It is key that the experiences of children, young people and families/carers requires further research and focus by providers and commissioners in collaboration with the public to improve outcomes.

These recommendations were developed by a group of charities who are experienced in supporting children, young people as well as their carers and families, and are endorsed by:



