Ensuring positive experiences of health and social care for children and young people

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Early experiences matter
It is already known that negative experiences of health and social care at a young age can affect help seeking behaviour, anxiety levels and concordance, all of which have a direct impact on healthcare outcomes.

This can only be avoided if systematically capturing, understanding and acting upon younger people’s feedback becomes commonplace across health and social care.

“Giving every child the best start in life is crucial for securing health and reducing health inequalities across the life course. The foundations for virtually every aspect of human development – physical, intellectual and emotional – are laid in early childhood.”


In 2012, almost 15% of all NHS acute admissions were children and young people under the age of 19.

Despite making up such a large proportion of the NHS patient population, there are very few tools available to systematically gather feedback from younger patients. Why?

Gathering the views of children and young people can be a daunting prospect. It requires an approach that is specific to the needs and abilities of different ages, yet consistent enough to ensure high quality and comparable findings that can be used to improve experiences of care. The experiences of parents and carers should also be collected. However where possible we must ensure this does not replace the ‘child’s eye view’ of care.

At Picker Institute Europe we partner with leading NHS children’s hospitals as well as organisations such as the Royal College of Paediatrics and Child Health to ensure the best understanding of children and young people’s experiences of health and social care. We sit on the NHS England steering group which aims to prioritise capturing and responding to children and young people’s experiences of care.

We develop comprehensive toolkits which enable the effective collection of feedback across all groups, whilst ensuring results are meaningful and actionable. Alongside this we run surveys for paediatric inpatient, outpatient, emergency, community and neonatal services.
Not just another target

Only sustained changes in behaviour can make a real difference to children and young people’s experiences of care. User experience programmes alone cannot claim to deliver the promise of a positive experience for children and young people, but good programmes can help to ensure high quality care.

To be effective programmes must:

- Be part of an organisational culture where patients are the priority;
- Be clearly defined in the organisation’s strategy, communicated to both staff and patients;
- Use appropriate mechanisms to collect and communicate user experience data in a way that engages and empowers staff to act on the findings; and
- Be dedicated to continuous improvement.

Find out what children and young people are telling us about their care.
What do we know about young people’s experience of care?

Our toolkits
Picker Institute Europe’s paediatric toolkits include a number of surveys designed to obtain feedback about the health experiences of young patients and service users.

These tools have been developed to cover the range of services accessed by children and young people, including:

- Paediatric inpatient, outpatient and emergency department
- Transition (and the transfer of care to adult services)
- Neonatal
- Community services

These tools have been developed to ensure the data you collect is robust, representative and comparable, allowing you to:

- Benchmark results
- Monitor performance over time
- Compare results across different sites
- Identify areas for improvement
- Put actionable improvement plans in place

What are staff telling us?**

- 23% of staff did not feel satisfied with the quality of work and patient care they were able to deliver
- 91% of staff agreed that their role makes a difference to patients
- Over 1/3 said they have witnessed potentially harmful errors, near misses, or incidents in the past month
- 71% feel they are able to contribute towards improvement at work
- 23% of staff did not feel satisfied with the quality of work and patient care they were able to deliver

What do we know about young people’s experience of care?*

* Data taken from Picker Institute Europe’s surveys on paediatric experiences of inpatient, outpatient or emergency department care in 2012.
** Data taken from Acute Specialist Paediatric Trust results for the 2013 NHS Staff Survey.
Ensure a rounded perspective

Programmes should be designed to gather feedback directly from children and young people whenever possible, however we must recognise that children’s experiences of care are also experiences for their parents and carers.

Our 2012 Paediatric Inpatient Survey found that 59% of parents or carers felt the ward was ‘definitely’ designed well for their child’s age group. This compared with just 34% of young patients.

This difference highlights the importance of gaining a rounded perspective, as often our perceptions as adults are not always the same as those of children.

Measure experience over satisfaction

As in our work with adults, we believe that research with children and young people must aim to examine experience rather than simply measure satisfaction.

Many programmes are very effective at uncovering how ‘satisfied’ or ‘happy’ individuals were with the care they received. However, they often fail to uncover the experiences or events that led to that positive or negative response.

Without this insight it is impossible to know why people were satisfied or dissatisfied; happy or unhappy; and what changes must be implemented to maintain or improve care.

Our toolkits use experience based questions to ensure we can support organisations to uncover the behaviours and/or environments which cause a positive or negative experience.
Be appropriate and engaging

The appropriateness of the tools and questions we use significantly affects their potential to collect high quality experience data. If not appropriate for the audience, respondents may misinterpret the meaning of questions, be unable to give answers, and/or decline to give their feedback.

Just as importantly feedback tools must be engaging to their audience. Using simple animated characters can be very effective in gathering feedback from younger patients, however they are unlikely to work as well for a 15 year old patient.

Similarly, that teenage patient may not be able to engage fully with a feedback tool designed for adults.

We test all of our toolkits with children and young people, getting their opinions on everything from the overall look and feel, to their interpretation of specific questions.

We also seek the opinions of leading professionals in paediatric medicine to ensure a rounded endorsement.

 Produce actionable results

Results must be presented in a format and at a level that is useful to staff.

Tables, charts and targets all have their place, but the focus on appropriateness and engagement applies as equally when presenting results to staff as it does when considering mechanisms to collect feedback from patients and service users.

- Using experience questions helps to ensure staff can easily link results to behaviours both as individuals and as teams.

- Reporting solutions designed and built in collaboration with staff, with regular refreshes of data, drive acceptance and usage

- The ability to benchmark against other areas of the organisation and/or other organisations, promotes the identification and sharing of best practices.

We believe achieving dedication to continuous improvement is key to maintaining long term engagement from staff.

We are committed to supporting you to use findings to underpin innovative and collaborative mechanisms, such as ‘Always Events’, ‘Patient Stories’, ‘You Said, We Did’ initiatives and ‘patient collaboratives’. These serve to maintain an appetite for, and engagement with, high quality data that is used as the fuel to drive behavioural change.

This ultimately ensures that a positive experience of health and social care is everyone’s experience.