

NHS Patient Survey Programme

2018 Children and young people's patient experience survey

Statistical release

Published November 2019

Independent data analysis

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Summary of findings

For children and young people, a hospital admission can be a daunting experience. The quality of the care they receive can inform their future relationship with health care professionals for many years to come. Understanding the quality of children and young people's hospital experiences is just as important as understanding the experiences of adults. Our survey gives children and young people an opportunity to feedback directly about their own experiences.

The 2018 Children and young people's patient experience survey asked children and young people about the quality of their care in hospital during November and December 2018. Respondents were children and young people aged 8 to 15 and their parents, and the parents of children aged 0 to 7. We received completed questionnaires about the experiences of 33,179 children and young people. This includes responses from 10,927 children and young people aged 8 to 15, who told us about their experiences through questionnaires specifically designed for them.

For the first time, we have been able to consider changes over time, comparing results for this survey with the 2016 iteration for most questions. With only a few exceptions, we found that experiences of children, young people and their parents and carers were almost unchanged in most areas this year.

Most experiences were positive overall, most children thought they were well looked after and that staff were friendly. However, a small number of children continue to be cared for on adult wards. Importantly, children who stayed on adult wards were less likely to report that there was enough to do, and their parents were less likely to report that their child's individual needs and preferences were respected. Moreover, parents of children with a mental health condition reported poorer experiences of overall care, respect for their child's needs and preferences, and their own involvement in their child's care. This follows a pattern of people with mental health conditions reporting poorer experiences of care than others in the 2018 Adult inpatient survey and the 2018 Urgent and emergency care survey.

Children and young people, as well as their parents, were generally positive about basic communication, information before operations, feeling able to ask staff questions and the answers they received to their questions. However, many children and young people reported that they did not feel involved in decisions about their care, were not able to play or do any activities with staff and that there were not enough things to do in the hospital.

As in other recent national patient surveys, children, young people and their parents reported comparatively poor experiences on questions about their discharge from hospital. For example, some children were not told how to look after themselves when they went home or who to talk to if they were worried, and some parents did not definitely know what would happen next with their child's care.

Experiences of children and young people

Positive results

Generally, children and young people remained positive about most aspects of their care in hospital.

The majority of children and young people aged 8 to 15 reported positive experiences overall. Most felt that they had **been looked after** 'very well' or 'quite well' (91%). Most felt that the people looking after them were 'always' friendly (87%); just one in 100 thought they were not friendly.

Children and young people told us that **communicating with staff** continues to be a particularly positive area of experience. The majority of children and young people aged 8 to 15 (95%) felt that they were able to ask questions and 92% of those who asked questions received an answer from staff – fewer than one in 200 said that hospital staff did not answer their questions. Moreover, 85% reported that staff talked with them about how they would be cared for. Of those who had an operation or procedure, 93% said they received an explanation about what would happen.

Results around **privacy and confidentiality** were also notably positive, as most young people aged 12 to 15 (90%) were able to talk to a doctor or nurse without their parent or carer being there if they wanted to. Just 2% of children and young people aged 8 to 15 said that they did not have enough privacy when receiving care and treatment. These figures are almost unchanged from 2016.

Most children and young people felt **emotionally supported** while in hospital – 92% of those who had worries said that staff talked with them about them.

Areas for improvement

Although there were areas of sustained positive experience around communicating with children and young people and answering their questions, **information** is still not always provided in an accessible and comprehensible way. Although a significant improvement on 2016 (68%), only 71% 'always' understood what staff said in 2018. Children aged 8 to 11 still have poorer experiences than young people aged 12 to 15 in this area.

In addition, results again show that children and young people do not feel fully and consistently **involved** in decision making. Fewer than half (46%) of all children and young people thought they had been involved 'a lot' in decisions about their care and treatment; around one in six (15%) said they had not been involved. However, results were significantly better than those in 2016, with most pronounced improvements for children aged 8 to 11.

Being **able to play and having enough to do** on the ward were two further areas where children and young people reported poorer experiences. Just under two in five (39%) children aged 8 to 11, who had wanted to, said that staff did not play or do any activities with them. Half of all children and young people said there were not enough things for them to do. Assessed for the first time this year, just four in 10 children and young people (41%) who used hospital Wi-Fi said that it was 'always' good enough

to do what they wanted. Children and young people who said that the Wi-Fi was 'always' good enough, however, were more likely to say there were enough things for them to do in hospital.

With regards to the **hospital environment**, three in 10 (31%) young people aged 12 to 15 did not fully agree that the ward was suitable for someone their age. Of those who needed to sleep, around one in five children and young people aged 8 to 15 (17%) said that it had not been quiet enough to sleep in the hospital.

Children and young people's experiences of **pain management** are unchanged from 2016. Just over one in five children and young people (21%) who felt pain while in hospital did not fully agree that staff had done everything they could to help them.

Children and young people's experiences of being **discharged** from hospital were not significantly different from their experiences in 2016 and remain some of the least positive areas of care. Two in 10 (21%) did not fully agree that they were told how to look after themselves when they went home. Nearly one in five children and young people (17%) reported that they were not told by staff who they should talk to if they were worried when they got home and over one in 10 (11%) said they did not know what would happen next. Children aged 8 to 11 reported significantly less positive experiences for both of these areas compared with young people aged 12 to 15.

Experiences of parents and carers

Positive results

Though comparatively less positive than children and young people, most parents felt that their child's **overall experience** was positive, with 80% rating it as eight or more out of 10. Results also showed positive experiences this year for parents' and carers' interactions with staff, as most said that they 'always' had confidence and trust in members of staff treating their child (80%), felt that they were friendly (81%) and that they were treated with respect and dignity (86%).

Parents and carers thought **basic aspects of communication** with staff about their children were positive. Most parents (91%) said that staff had agreed a plan for their child's care with them. Just two in 100 (2%) parents said that were not able to ask staff questions about their child's care. Most parents said that staff gave them information about their child's care and treatment in a way they could understand (82%).

Communication before operations and procedures was an area of particularly positive experience for parents. Ninety per cent of parents and carers of children of all ages said that staff 'completely' explained what would be done and, again, 90% said that staff had answered their questions about operations or procedures in a way they could understand.

Areas for improvement

Parents and carers reported poorer experiences around [information relating to coordination of their child's care](#). A third of parents and carers of children aged 0 to 7 (34%) said that staff had given them conflicting information 'sometimes' (24%) or 'a lot' of the time (10%, a significant deterioration compared with 2016). For all parents and carers, three in 10 (30%) did not 'definitely' think staff had kept them informed about what was happening while their child was in hospital. Over four in 10 (42%) did not think that staff were 'definitely' aware of their child's medical history.

Parents' experiences of [hospital facilities](#) still have room for improvement, as over a third (36%) of all parents who had wanted to prepare food in the hospital were not able to, although this percentage was significantly lower than in 2016 (38%).

As in 2016, a small proportion of parents and carers (1%) reported that their child [stayed on an adult ward](#). Demonstrating room for improvement for young people's transition to age-appropriate facilities, only 9% of parents of young people aged 12 to 15 said that their child had stayed on a teenage or adolescent ward. Fewer than two thirds (63%) of all parents thought staff were 'always' available when their child needed attention.

There were significant improvements around the [information parents and carers received at discharge](#) this year. However, nearly three in 10 (29%) parents did not 'definitely' know what would happen next with their child's care and one in five parents (22%) did not 'definitely' think that staff had given them advice about how to look after their child when they got home. Results for both of these questions improved by two percentage points from 2016.

In many areas, parents of children aged 0 to 7 reported worse experiences than the parents of children and young people aged 8 to 11 and/or 12 to 15 – even in areas where experiences are poorest. For example, while 66% of parents of children aged 8 to 11 and 65% of parents of children aged 12 to 15 said staff were 'definitely' aware of their child's medical history, this figure was 55% for parents of children aged 0 to 7. A second example, while 68% of parents of children aged 8 to 15 thought staff were 'always' available when their child needed attention, this figure was 61% for parents of children aged 0 to 7.

How experience varies for different patient groups

A [subgroup analysis](#) revealed that some patient groups reported notably poorer care in a number of areas.

Parents and carers of children with mental health conditions reported significantly poorer experiences on questions concerning welcoming the involvement of family and friends, had significantly poorer perceptions of their child's overall care, and reported more negative experiences on questions concerning respect for their child's individual needs and preferences. These findings for patients with a self-reported mental health condition are similar to those in 2016 and echo the results of similar analyses of other NHS patient surveys, such as the 2018 Adult inpatient survey and the 2018 Urgent and emergency care survey.

Parents and carers who reported that their child has a developmental disability, a neurological condition, or 'another long-term condition', reported more negative experiences on questions concerning respect for their child's individual needs and preferences.

As in 2016, children and young people who stayed on an adult ward reported significantly poorer experiences on the question, 'Were there enough things for you to do in the hospital?'. Again, as in 2016, parents and carers of children who stayed on an adult ward reported significantly poorer than average experiences for questions concerning respect for their child's individual needs and preferences.

Experiences varied by ethnicity in two areas. Parents and carers of Asian children reported significantly poorer experiences around feeling able to raise concerns. Parents and carers of Black children also reported significantly poorer experiences on feeling that they, as a parent, had been well looked after.

Notably more positive experiences of care emerged for only one group of patients and in one area: parents of children who had cancer in the last five years reported more positive experiences of staff being aware of their child's medical history.

Introduction

Importance of patient experience

The importance of a positive patient experience is increasingly recognised across the NHS and within government health policy. Research has found that patient experience is linked to better clinical outcomes, safety and effectiveness.¹

Many different aspects of a patient's care contribute to their experience in hospital. In 2012 the NHS National Quality Board published the [NHS Patient Experience Framework](#) to highlight important elements of a patient's experience.² These include respect and involvement, coordinated and integrated care, information and communication, physical comfort and emotional support. NHS Improvement's [Patient experience improvement framework](#) and the National Institute for Health and Care Excellence's guideline [Patient experience in adult NHS services](#) provide healthcare organisations with standards, guidance and recommendations on improving experiences.^{3,4} The [NHS Outcomes Framework's](#) national patient experience indicators are designed to help ensure that people have a positive experience of care.⁵

The [NHS Constitution](#) commits to actively encouraging feedback from patients to improve services.⁶ Similarly, the [NHS Mandate 2018 to 2019](#), [NHS Long Term Plan](#) and the National Quality Board's [Shared Commitment to Quality](#) all emphasize the importance of collecting and using feedback to enhance the overall quality of services.^{7,8,9} Children and young people's feedback is just as important as adults' and it is important that young patients' voices are heard. However, historically, children and young people have had few ways to directly feedback on their care. This has led to a lack of information on their experiences compared with adults, underrepresentation in quality indicator frameworks, and a shortage of dedicated patient experience guidelines.^{10,11,12} Secondary analysis of the 2014 national children's survey has highlighted the added value of seeking the views of children and young people directly.¹³

This survey

The Children and young people's patient experience survey is part of a wider programme of NHS patient surveys, which covers a range of topics including maternity, adult inpatient, emergency and urgent care and community mental health services. To find out more about the NHS Patient Survey Programme, please see the [further information and feedback section](#).

The 2018 survey is the third national survey to focus on children and young people's experiences of hospital care in the NHS since 2014. Following substantial revisions in 2016, the survey methodology remains unchanged this year, allowing historic comparisons for the first time. This 2018 statistical release presents the key results from the survey and highlights statistically significant differences compared with 2016.

Wherever possible, questions remain the same over time to measure change. However, when necessary, questions are modified or removed to reflect changes in policy, methodological best practice, and stakeholder feedback during development. The questionnaires used in the 2018 survey were broadly similar to those used in 2016, substantially modified in just a few areas. Two questions were removed (both on medicines) and three new questions were added (two on Wi-Fi and one on parents feeling able to raise concerns). The children and young people's sections of the questionnaires featured new illustrations. The long-term condition question was improved and brought in line with the new standard format for NHS Patient Survey Programme questionnaires. For full details, please see the [Survey Development Report](#).

Background to the survey

Participants in the survey

The 2018 Children and Young People's Patient Experience Survey involved 129 NHS acute trusts in England, who sent questionnaires to 134,021 patients. We received completed questionnaires about the experiences of 33,179 children and young people, an adjusted response rate of 25%.

Trusts selected a sample of up to 1,250 admitted patients aged 15 days to 15 years at the time of discharge, who received care in hospital during November or December 2018^a. The target for a trust's sample size was set at 450 patients aged 0 to 7 and 400 each for those aged 8 to 11 and 12 to 15. This approach reflects the lower response rate in previous years for the 0 to 7 age group. Where a trust was unable to achieve these targets, they were permitted to include eligible patients from any other age group, where available, up to 1,250 in total.

The survey featured three separate questionnaires, with each developed to meet the needs of the target age group. Questionnaires sent to those aged 8 to 11 and 12 to 15 featured separate sections for the child or young person and their parent or carer. Where a child was aged 0 to 7, the questionnaire was completed entirely by their parent or carer.

Fieldwork for the survey (the period during which questionnaires were sent out and returned) took place between February and June 2019.

Eligible patients included those who were admitted as an inpatient, either on a planned basis through a waiting list or as an unscheduled emergency admission. Day case patients (i.e. those who attended hospital as a planned admission and were discharged on the same day) were also included.

The following groups of patients were excluded:

- patients who were not admitted to hospital (for example, those who attended a ward or who attended an outpatient appointment but were not admitted)
- patients who had died
- patients aged 16 years or older at the time of their discharge
- babies aged between 0 and 14 days at the time of their discharge
- newborn babies whose mother was the primary patient (well babies, treatment function code 424)
- patients who were only admitted to a neonatal intensive care unit (NICU) or a special care baby unit (SCBU) (treatment function code 422)
- obstetrics/maternity patients, including spontaneous miscarriages

^a Five trusts were permitted to sample patient discharged in October 2018 due to a low number of eligible patients discharged in November and December.

- patients admitted for planned termination of pregnancy
- psychiatry patients, including those receiving care from child and adolescent mental health services (CAMHS)
- private patients (non-NHS)
- NHS patients treated at private hospitals
- any patients who were known to be inpatients at the time of sampling
- patients without a UK postal address
- any patient, parents or carers who had requested that their details were not used for any purpose other than their clinical care (note, however, that those who had opted-out through the national data opt-out service were eligible).

The survey also collected basic demographic information for all patients who took part, which is available in the 'About the respondents' section in the Quality and methodology report (see link in [appendix C](#)).

Policy context

It is important to consider the landscape of hospital care for children and young people in England when the survey was carried out. This section summarises key policies and the wider context of children and young people's NHS care.

Standards and quality

The Department of Health's [National Service Framework for Children, Young People and Maternity Services](#) (2004) remains the foundation of children and young people's healthcare policy in England.¹⁴ [Getting the right start: National Service Framework for Children - Standard for Hospital Services](#) (2003) is the most comprehensive policy guidance for hospital care.¹⁵ Building on this, the more recent [You're Welcome - Quality criteria for young people friendly health services](#) (2011) lays out key principles for young person-friendly health services.¹⁶

The Care Quality Commission's (CQC) annual report [The state of health care and adult social care in England 2018/19](#) shows that the majority of NHS non-specialist services for children and young people are providing good care, with 78% of services rated as good and 4% rated as outstanding.¹⁷

The Care Quality Commission's [State of care in NHS acute hospitals: 2014 to 2016](#), a review of CQC's programme of comprehensive hospital inspections, reported that children and young people's services during this period were often rated better than other [hospital core services](#).¹⁸ For example, some trusts that were rated as inadequate overall, were rated good or outstanding for their children and young people's services. Moreover, where inspections identified issues with the care of children and young people, they were often attributable to other core services such as surgery or outpatients.

Growing recognition, and influence, of children and young people

There is growing recognition that children and young people's patient experience needs are different from adults. This increasing awareness will be formalised by the forthcoming NICE guideline [Babies, children and young people's experience of healthcare](#) — a counterpart guideline to *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services*¹⁹, tailored, for the first time, to children and young people's care. Scheduled for publication in 2021, the guideline will feature both over-arching and specific recommendations for different age groups on key aspects of children and young people's care experiences, such as communication, consent, privacy, involvement of parents and carers, facilities and their inclusion in the planning and designing of healthcare services.

The care of children and young people and the improvement of their health and wellbeing is a priority in the [NHS Long Term Plan](#).⁸ In addition to securing focused improvements to maternity services, mental health services for children and young people, and the care of children and young people with common long-term conditions, the Plan set out its ambitions to create a Children and Young People's Transformation Programme. This will work towards more general commitments, which include:

- improvements in childhood immunisation
- a reduction in unnecessary emergency department attendances by children and young people, through increased access to local primary or community care
- improvements in the quality of care for children with long-term conditions
- changes to critical paediatric care and surgical services to provide a coordinated approach in both
- establishing a '0 to 25 years' service, that will enhance children and young people's care experiences, outcomes, and continuity by avoiding arbitrary or premature transitions to adult services.

At the same time, children and young people are a growing influence on healthcare services in England²⁰. The NHS Youth Forum, established in 2013, is increasingly enabling young people to shape healthcare services and to understand what they can expect when they use those services.²¹ For example, the [Youth Rights in Healthcare](#) sets out young people's rights to confidentiality, consent, and provide feedback on their care²². At a local level, a growing number of NHS trusts have dedicated youth forums or child patient panels.^{23, 24}

Increased demand for services

In line with other population groups, more children and young people have continued to access health services over time. For example, [Hospital Episode Statistics](#) (HES) published by NHS Digital show an increase of 165,270 accident and emergency (A&E) department attendances among those aged 0 to 14 years between 2017-18 and 2018-19.²⁵ In 2018–19, the 4.68 million attendances for those aged 0 to 15 accounted for 17% of total A&E attendances nationally.

According to the Royal College of Paediatrics and Child Health, staff numbers have not kept pace with the increased demand for services.²⁶ In 2018, the college estimated that at least an additional 752 whole time equivalent paediatric consultants were required to achieve targeted service standards. In addition, the college also warned that nation-wide declines in numbers of general practitioners and nurses also pose challenges to children's care. Wider staffing shortages, amidst growing demand for services due to a growing and ageing population, are recognised in the [Interim NHS People Plan](#).²⁷

Mental health and long-term conditions

According to the [Health Survey for England 2017](#), just under one in six (16%) children and young people aged 0 to 15 have a longstanding illness.²⁸ Similarly, [The mental health of children and young people in England](#) estimates that 10% of children and young people aged between 5 and 16 suffer from a clinically significant mental health condition.²⁹

The government's [Revised mandate to NHS England 2018-19](#) recognises the need to improve the quality of care for people with mental health problems, with an objective to reduce the health gap between people who have a mental health condition, a learning disability or autism, and those that do not.³⁰ Changes to children and young people's mental health services are considered key to this aim. [Future in Mind: Promoting, protecting and improving our children and young people's mental health and wellbeing](#) and [The Child and Adolescent Mental Health Green Paper](#) also highlight the need to do more for children and young people with mental health conditions.^{31,32}

National patient surveys, such as the [2018 Urgent and emergency care survey, 2018 Adult inpatient survey](#) and [2016 Children and young people's survey](#), have repeatedly found that patients with a mental health condition or long-term physical condition report poorer experiences of care.^{33,34,35}

Staffing levels

It is essential that NHS providers have the appropriate number and mix of clinical professionals to ensure that they are able to deliver high-quality care and protect patients from avoidable harm.³⁶ Research has shown that the experiences of healthcare staff are linked to the quality of care that patients receive.^{37,38}

The Royal College of Nursing provides guidance and standards to be applied in all services providing health care for children and young people. For example, a minimum of two registered children's nurses and one play specialist should be available at all times in all inpatient and day case areas. Furthermore, services for children should have 24-hour access to a senior children's nurse.³⁹ The National Quality Board's [Safe, sustainable and productive staffing: An improvement resource for children and young people's inpatient wards in acute hospitals](#) provides guidance on improving the staffing of children and young people's inpatient wards and other hospital services to achieve these standards.⁴⁰

Integrated care

As set out in CQC's [The state of health care and adult social care in England 2017-2018](#), access to good health and social care in England increasingly depends on how well local health systems work together.⁴¹

In 2014, [The Five Year Forward View](#) set out ambitions for the NHS to introduce new models of care 'integrated around the patient'.⁴² Since 2015, the [Better Care Fund](#) (BCF) has supported the integration of NHS and local authority health and social care services.⁴³ Most recently, [The NHS Long Term Plan](#) outlined plans for Integrated Care Systems (ICS) comprised of neighbouring NHS organisations and commissioners. ICSs will unite local organisations to redesign care and improve health in their area and commit to system-wide healthcare improvement aims, to which multiple providers will contribute.⁸

[You're Welcome - Quality criteria for young people friendly health services](#) requires information to be shared to facilitate joined-up working. This means that all staff need to be familiar with local service provision and arrangements for referral.¹⁶ The Department of Health and Social Care's standard for hospital services [Getting the right start: National Service Framework for Children](#) also highlights the importance of the integration and coordination of services, and recommends a coordinated care package for each child and young person who requires more than the 'simplest of hospital care'.¹⁵ In such cases, through joint planning by primary care services, relevant hospital departments, educational and social services, care teams should provide a joined-up care package that allows children, young people and their families to easily access different services after discharge. The World Health Organization's [Standards for improving the quality of care for children and young adolescents in health facilities](#) stresses the importance of coordinated care and the key role of the successful exchange of information between health professionals during patient handover.⁴⁴

The CQC's [State of care in NHS acute hospitals: 2014 to 2016](#) reported that, although there were some exceptions, few hospitals have well established services to help children with long-term conditions when they transition to adult services.¹⁸ [The NHS Long Term Plan](#) seeks to correct this by establishing '0 to 25 years' services designed to avoid difficult and premature transition.⁸ Guidelines from the National Institute for Health and Care Excellence (NICE) [Transitioning from children's to adults' services](#) recommend that young people with a long-term condition or mental health condition should begin this process from the age of 13 to 14 years (school year nine).⁴⁵ Starting at this age gives a young person time to be involved in decision-making and allows them to prepare for future changes to their care.

Results from the survey

This section presents the results for the 2018 Children and young people's patient experience survey. Statistically significant differences between age groups, comparing results for those aged 0 to 7, 8 to 11 and 12 to 15, and survey years are highlighted where possible. We use an asterisk (*) to indicate statistically significant within-year age group differences in tables of results and arrows (↑↓) to indicate statistically significant differences between 2016 and 2018.

To understand how patient experience varies between different groups of patients, we included an additional subgroup analysis in this section. The Equality Act 2010 legally protects people from discrimination when using public services and extends to the family and friends of anyone who has a protected characteristic. The protected characteristics we were able to assess in the survey results include age, sex, disability and ethnicity. Differences between people's experiences have also been assessed by proxy response (whether the parent or carer completed the children's questionnaire on behalf of their child); whether a patient received medical or surgical care while in hospital; overnight stay (whether the patient was an inpatient or day case); the type of ward the patient stayed on (children's, teenage/adolescent, or adult); and the number of times they stayed in hospital in the past six months (once, two or three times, or four times or more).

There is a full summary of results in [section 9](#).

Survey results are organised under the following key themes:

1. [Admission to hospital](#)
2. [Hospital and ward](#)
3. [Doctors and nurses](#)
4. [Facilities for parents and carers](#)
5. [Pain management](#)
6. [Operations and procedures](#)
7. [Leaving hospital](#)
8. [Overall](#).

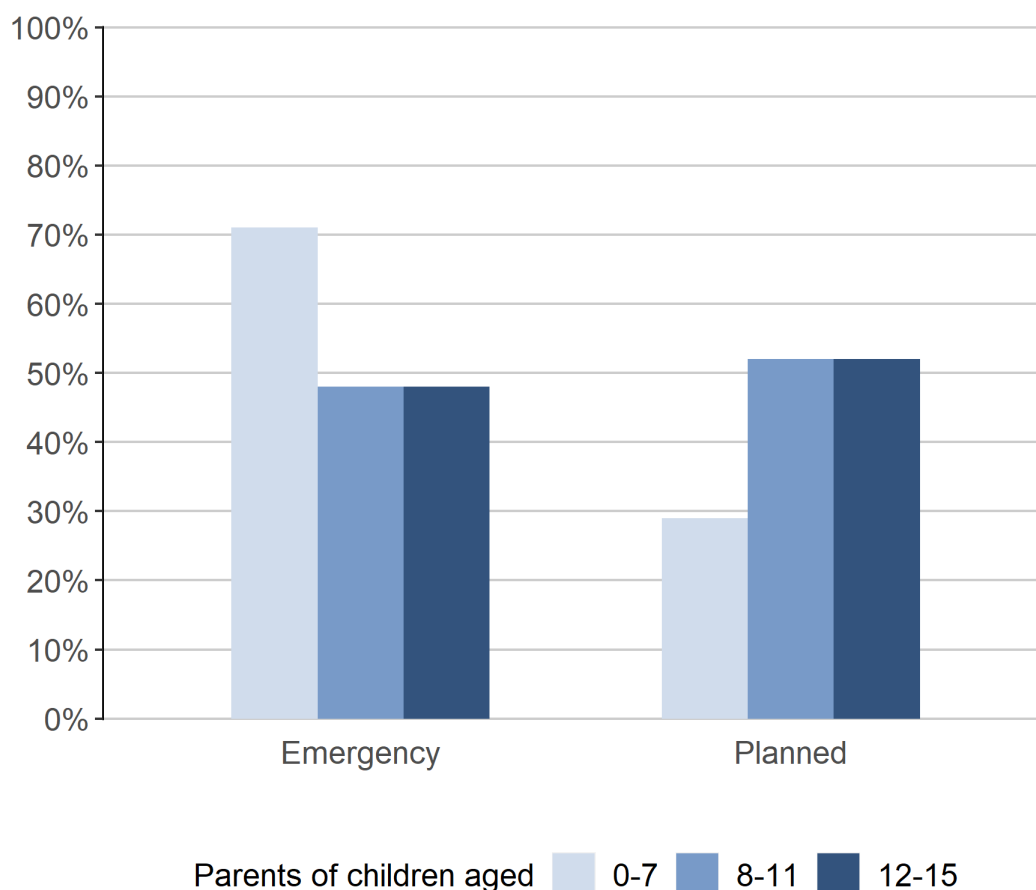
Please note, responses to questions such as 'don't know / can't remember' are not shown or included in percentage calculations. The wording for these responses is designed for when a respondent cannot remember or does not have an opinion. Percentages are rounded to the nearest whole number.

1. Admission to hospital

The [NHS Patient Experience Framework](#) identifies access to care and the time spent waiting for admission as important aspects of patient experience.² [The Government's revised mandate to NHS England for 2018-19](#) recognises timely access to care as a key principle of the NHS and the [NHS accountability framework 2019-20](#) asks NHS England to reduce elective waiting lists.^{30,46}

As in 2016, a child or young person's admission was more likely to have been an emergency (64%) than planned (36%). This is driven by the high proportion (71%) of children aged 0 to 7 admitted as emergencies, a statistically significant increase from 2016 (69%). Figure 1 shows that the admission profile of children aged 8 to 11 and 12 to 15 is, however, more balanced — for both groups, 48% emergency and 52% planned in 2018.

Figure 1. Response percentages for X2: Was your child's visit to hospital planned or an emergency? by age



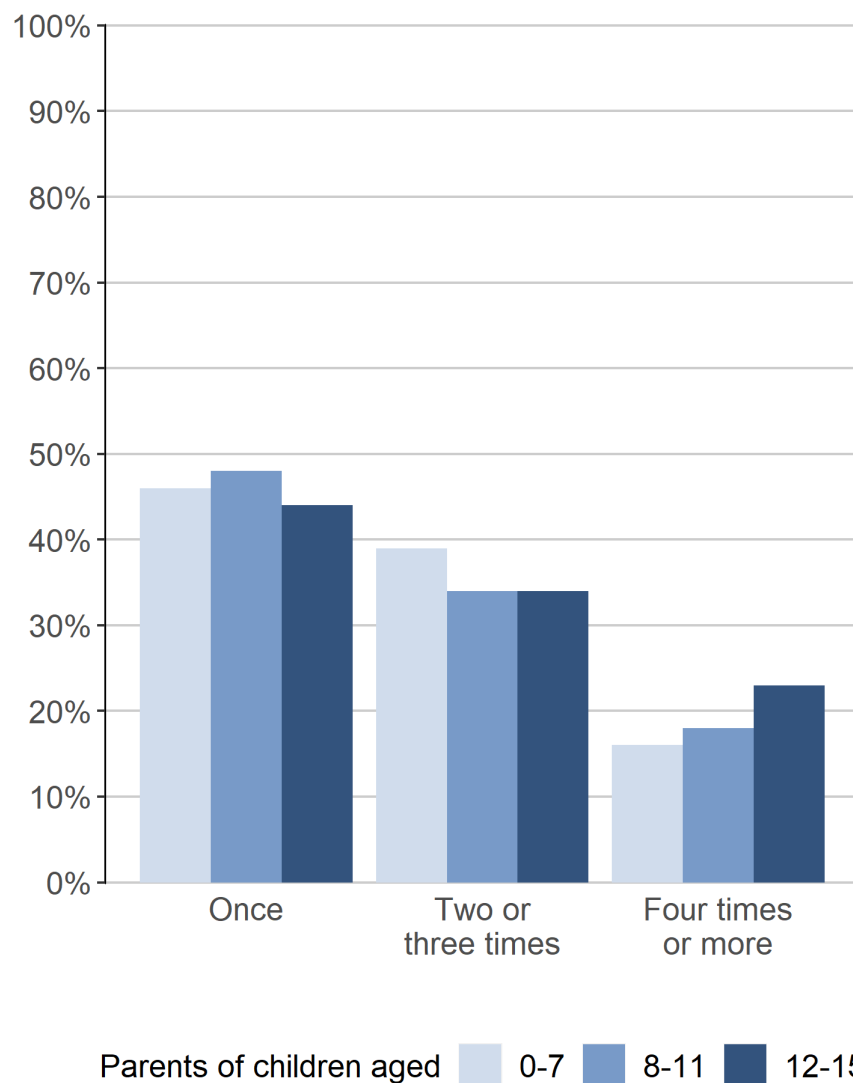
Note: respondent numbers: parents of children aged 0 to 7 (23,564), parents of children aged 8 to 11 (4,112), parents of young people aged 12 to 15 (4,815).

Parents and carers of children aged 0 to 7, who reported their child's admission was planned, were asked whether the hospital gave them a choice of admission dates. Two-thirds of respondents said 'no' (66%), a statistically significant increase compared with 2016 (64%). They were also asked whether the hospital changed

their child's admission date. The most common response was 'no' (83%), but over one in 10 said 'yes, once' (13%), and just under one in 20 said 'yes, a few times' (4%). These figures are unchanged from 2016.

More than half of parents of children aged 0 to 15 (54%) reported that their child had visited hospital more than once in the last six months. Almost one in five (18%) reported that, including this visit, their child had visited 'four times or more'. See figure 2 for results by age group.

Figure 2. Response percentages for X75: Including this visit, how many times has your child been to hospital in the past six months? by age



Note: Number of respondents: parents of children aged 0 to 7 (19,301), 8 to 11 (6,289), 12 to 15 (6,950).

2. Hospital and ward

Play and activities

The Department of Health and Social Care's (DHSC) standard for hospital services [Getting the right start: National Service Framework for Children](#) highlights the benefits of play for children in hospital, which include helping a child to process new information, adapt to a new environment and improving recovery time. It states that play should be encouraged, and that the child should have access to a variety of play interventions at each stage of their care journey.¹⁵ This is supported by the World Health Organization's (WHO) [Standards for improving the quality of care for children and young adolescents in health facilities](#), which states that children and young people should be provided with opportunities for age-appropriate play and recreational activities to promote psychosocial well-being and alleviate stress.⁴⁴

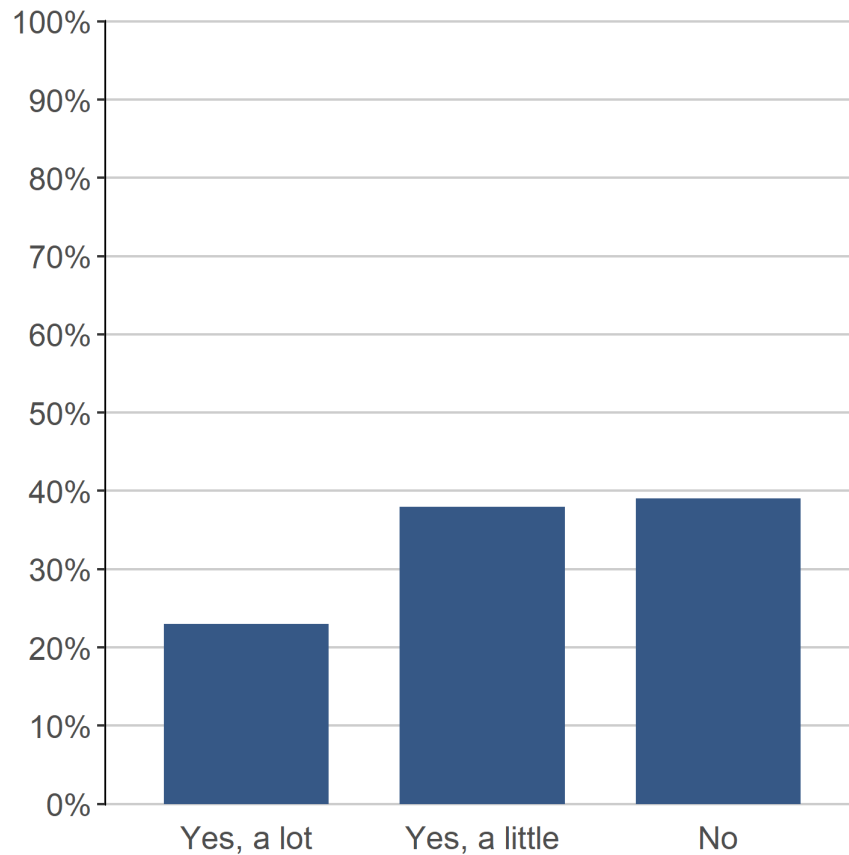
More generally, the right to age-appropriate play and recreation is recognised by Aspiration 8 of the [Charter for Children's Health Services](#) and Article 31 of the [United Nations Convention on the Rights of the Child](#).^{47,48}

The Royal College of Nursing's standards [Defining staffing levels for children and young people's services](#) require at least one play specialist for each inpatient ward.³⁹

Children aged 8 to 11 were asked whether the hospital staff played with or did any activities with them while they were in the hospital. Figure 3 shows that, of those who indicated that they had wanted to play, only around one in five (23%) said this happened 'a lot', with a further 38% saying staff played with them 'a little'. Almost two in five (39%) children aged 8 to 11 who wanted to play while in hospital said this did not happen. These percentages are not significantly different from those in 2016.

Parents of children aged 0 to 7 were more positive than parents of children aged 8 to 11 when asked whether staff played with their child while they were in hospital. Just under three quarters said 'yes' (73%) and just over a quarter of parents said 'no, but I would have liked this' (27%). Figure 4, below, shows there are small but statistically significant changes in these figures over time.

Figure 3: Response percentages for X48: Did hospital staff play with you or do any activities with you while you were in hospital?



Note: Answered by children aged between 8 and 11 years (2,742). Respondents who answered “I did not want or need them to” have been excluded.

Figure 4. Response percentages for X10: Did staff play with your child at all while they were in hospital? by survey year

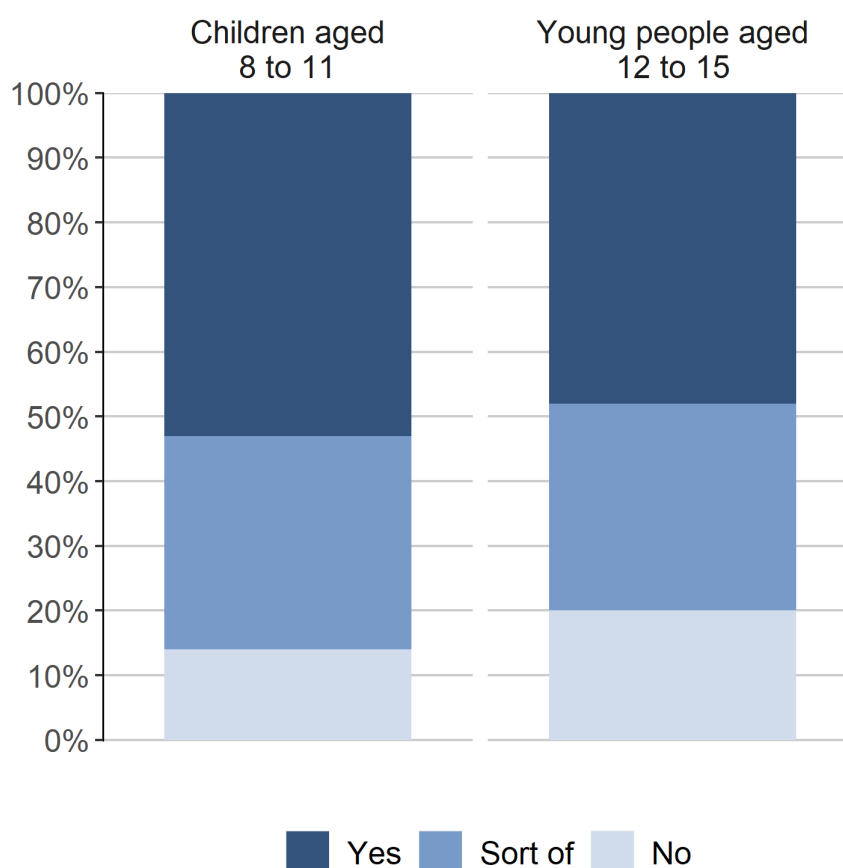
	Year		Significant difference between 2016 and 2018
	2016	2018	
Yes	74%	73%	↓
No, but I would have liked this	26%	27%	↑

Note: Answered by parents and carers of children aged 0 to 7 (13,775 in 2016; 13,212 in 2018). Parents who answered ‘No, but I didn’t want/need them to do this’ or ‘don’t know/can’t remember’ have been excluded.

Getting the right start: National Service Framework for Children calls for a range of age-appropriate equipment to be provided, including a bedside TV with headphones, a telephone, and a radio.¹⁵ The [You're Welcome: Quality criteria for young people friendly health services](#) reiterates the importance of recreational activities and recommends that recreational items, such as books and DVDs, should regularly be refreshed and maintained.⁴⁹

Children and young people were asked 'were there enough things for you to do in hospital?'. Of all children and young people aged 8 to 15, just 50% answered 'yes', 33% answered 'sort of' and 17% answered 'no'. Figure 5 shows that, as in 2016, the younger age group was more positive. While 53% of children aged 8 to 11 answered 'yes', the corresponding figure for young people aged 12 to 15 was lower at 48%. Similarly, 14% of children aged 8 to 11 answered 'no' (a statistically significant increase from 12% for this age group in 2016), the corresponding figure for young people aged 12 to 15 was 20%.

Figure 5. Response percentages for X50: Were there enough things for you to do in the hospital? by age



Note: Answered by children aged 8 to 11 (4,597) and young people aged 12 to 15 (5,410).

Parents of children aged 0 to 7 were more positive. Over half (61%) stated that there were 'definitely' enough things for their child to do in hospital. However, this is a statistically significant percentage decline from the 2016 survey (63%). Just under a

third (31%) answered 'yes, to some extent'. Fewer than one in 10 parents said 'no' (7%); compared with nearly one in five children and young people.

NHS digital's [Wi-Fi Programme](#) aims to deliver reliable Wi-Fi across the NHS, for the benefit of both patients and staff. The key benefits of using Wi-Fi in hospitals include helping the patient to remain connected to friends and family, interact with patient support networks, and use health apps.⁵⁰

Children and young people were asked, 'If you used the hospital Wi-Fi, was it good enough to do what you wanted?'. While most children said 'yes, always' (41%) or 'yes, sometimes' (40%), just under one-fifth of children said 'no' (18%). Figure 6 shows that children aged 8 to 11 were significantly more likely to respond with 'yes, always' (43%) than young people aged 12 to 15 (40%).

Figure 6: Response percentages for X51: If you used the hospital Wi-Fi, was it good enough to do what you wanted? by age

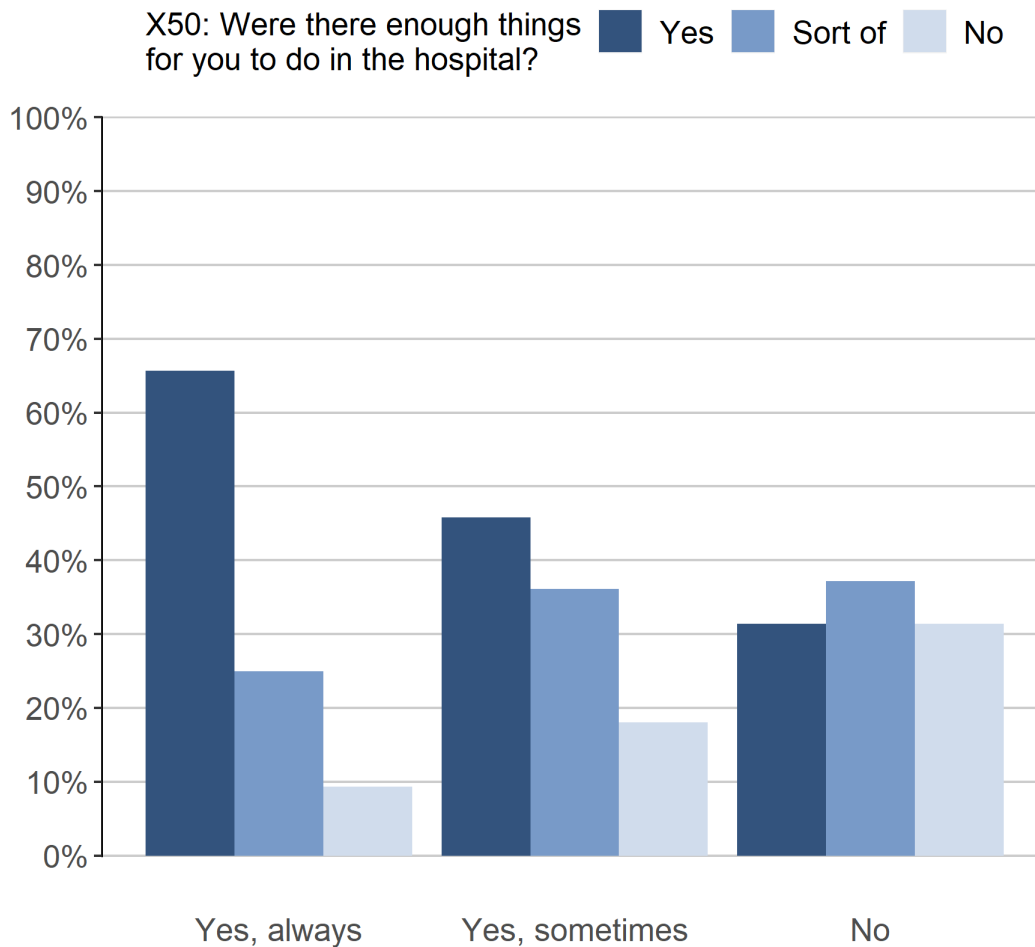
	Age group			Significant difference between: 8-11 & 12-15
	8-11	12-15	8-15	
Yes, always	43%	40%	41%	*
Yes, sometimes	38%	42%	40%	*
No	19%	18%	18%	

Note: Number of respondents: children aged 8 to 11 (2,709), 12 to 15 (3,566), 8 to 15 (6,275). Children and young people who answered 'I did not use Wi-Fi' have been excluded.

Parents and carers of children aged 0 to 7 were asked, if their child had used hospital Wi-Fi to entertain themselves, whether it was good enough to do what they wanted. Of the parents who indicated their child had used the Wi-Fi, 39% said 'no', it was not good enough, while a quarter of parents said 'yes, sometimes' (25%).

Figure 7 shows that children aged 8 to 15 were more likely to respond positively to the question 'Were there enough things for you to do in hospital?' if the Wi-Fi was good enough to do what they wanted.

Figure 7. X50: Were there enough things for you to do in the hospital? By X51: If you used the hospital Wi-Fi, was it good enough to do what you wanted?



X51: If you used the hospital Wi-Fi, was it good enough to do what you wanted?

Note: Percentages of children and young people aged 8 to 15 who answered both questions (6,125).

Food

As stated in standard 5 of the WHO [Standards for improving the quality of care for children and young adolescents in health facilities](#), access to healthy and culturally appropriate food and drink is essential for children and young people in hospital.⁴⁴ [Getting the right start: National Service Framework for Children](#), similarly states that providing enough food that meets the needs of children and young people is a priority, and that to encourage children to eat, they should be offered familiar meals that respect their cultural needs and preferences.¹⁵

To help improve food and drink in hospitals, NHS England published guidance on [Commissioning Excellent Nutrition and Hydration](#) and developed a toolkit of good practice, [A toolkit to support NHS commissioners to reduce poor experience of in-patient care](#), which includes guidance on preparing meals ‘from scratch’ and having

dedicated staff who focus on mealtimes and identify patients who may need extra nutrition.^{51,52}

Children and young people were asked whether they liked the hospital food. Overall, just over half answered ‘yes’ (51%). Figure 8 shows that, by age, children aged 8 to 11 were more positive than young people aged 12 to 15. While 54% of children aged 8 to 11 said that they liked the hospital food, this figure was 48% for young people aged 12 to 15. Likewise, a smaller percentage of children aged 8 to 11 answered ‘no’ (14%) than young people aged 12 to 15 (19%). For each age group, these figures are almost unchanged from 2016.

Figure 8: Response percentages for X52: Did you like the hospital food? by age

	Age group			Significant difference between: 8-11 & 12-15
	8-11	12-15	8-15	
Yes	54%	48%	51%	*
Sort of	32%	33%	32%	
No	14%	19%	17%	*

Number of respondents: children aged 8 to 11 (3,182), 12 to 15 (3,677), 8 to 15 (6,859). Children and young people who answered ‘I did not have hospital food’ are excluded.

The subgroup analysis (for details see [section 9](#)) included an analysis of children and young people’s evaluations of the hospital food. Children who had cancer in the last five years had significantly worse than average perceptions of hospital food. There were no other notable differences between groups of children or young people for this question.

Over a third of parents and carers of children aged 0 to 7 said that their child ‘definitely’ liked the hospital food (35%), which is a small but statistically significant decline from 2016 (36%). One in five (20%) reported that their child did not like the food and 45% said their child liked the food provided ‘to some extent’.

Environment

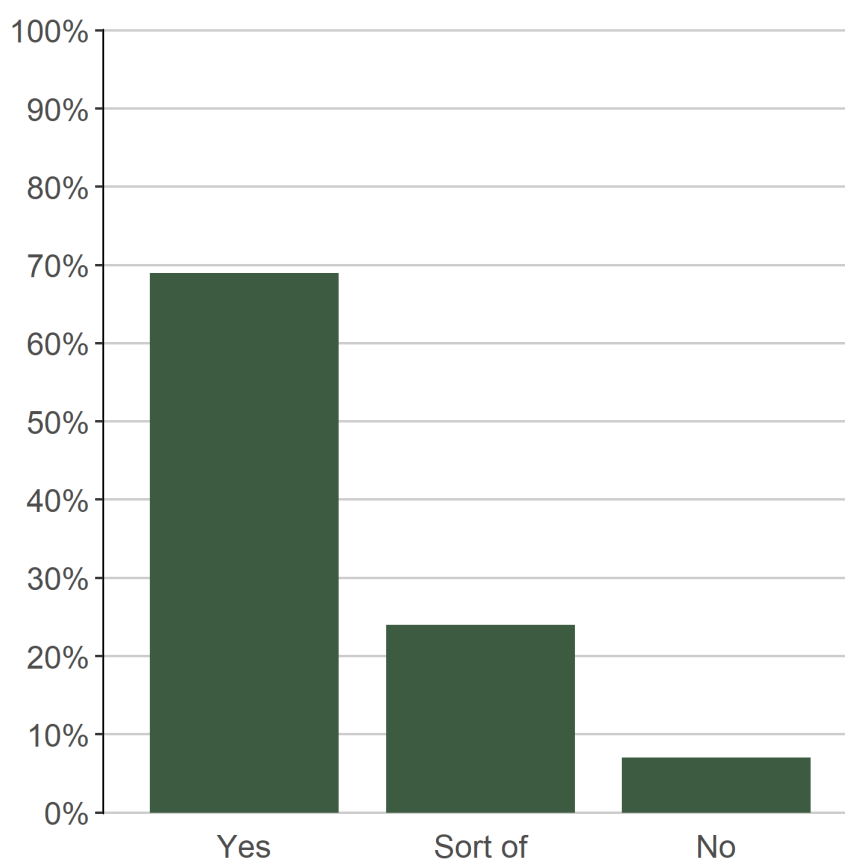
Research shows that a priority for children and young people is that they are cared for in hospital environments appropriate for their age and needs.^{53,54,55} This is recognised in the [Getting the right start: National Service Framework for Children](#) standard ‘quality of setting and environment’, which states that children should not be cared for on adult wards.¹⁵ Instead, they should be treated on wards appropriate for their age, stage of development, needs and preferences, with the needs of adolescents particularly requiring careful consideration.

Similarly, the child-friendly physical resources standard of the WHO [Standards for improving the quality of care for children and young adolescents in health facilities](#) states that hospitals should have dedicated care areas for children and adolescents that are separate from those for adults.⁴⁴

Ensuring that that treatment areas are friendly, comfortable and welcoming to children and young people is also a key criteria for quality in [You're Welcome](#).¹⁶

Young people aged 12 to 15 were asked whether the ward was suitable for someone their age. Figure 9 shows that just under seven in 10 said 'yes' (69%), just under a quarter said 'sort of' (24%) and fewer than one in 10 said 'no' (7%). These figures are not significantly different from 2016.

Figure 9: Response percentages for X49: Was the ward suitable for someone of your age?



Note: Answered by young people aged between 12 and 15 years (5,151 in 2018).

As in 2016, young people aged 12 to 15 were more likely to think the ward was suitable for someone their age if they had stayed on a teenage or adolescent ward (figure 10). While eight in 10 young people who stayed on a teenage or adolescent ward reported that the ward was suitable for someone their age (80%), that figure fell to two-thirds if they stayed on a children's (67%) or adult ward (66%). If they stayed on a teenage or adolescent ward, young people were also significantly less likely to say that ward was not suitable for someone their age: 3% versus 8% (a children's ward) and 9% (an adult ward).

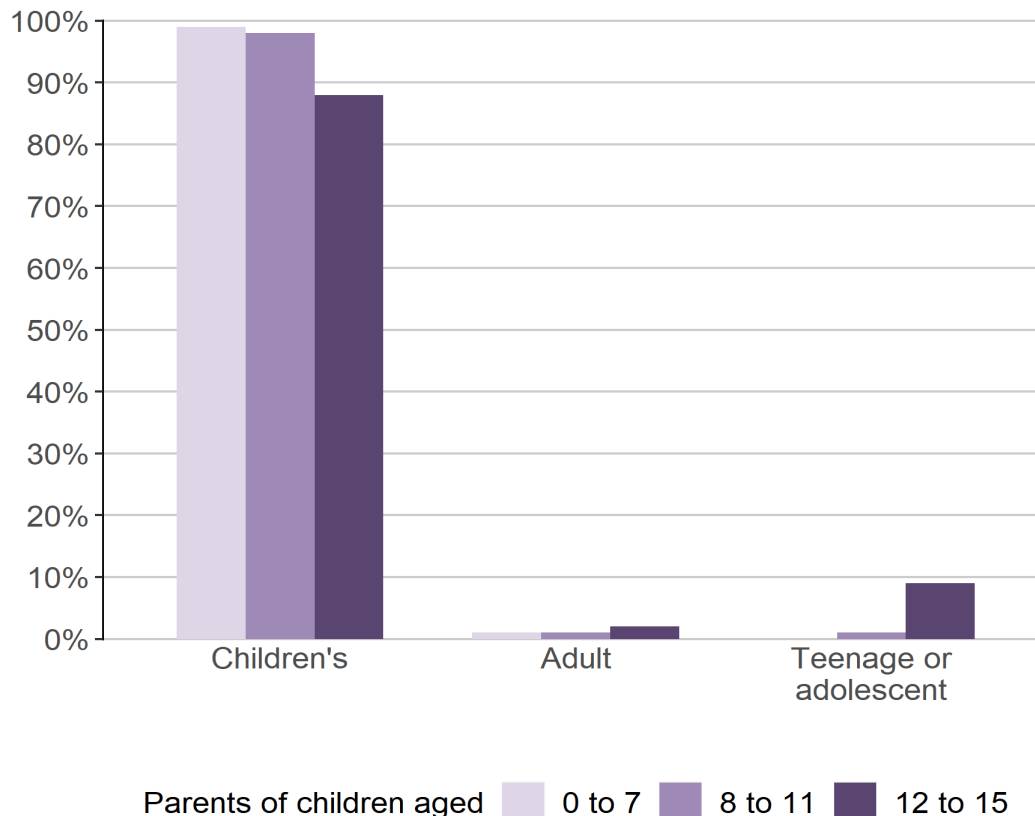
Figure 10. X49: Was the ward suitable for someone of your age? by X5: For most of their stay in hospital what type of ward did your child stay on?

		X5: For most of their stay, what type of ward did you child stay on?		
		A children's ward	An adult ward	A teenage / adolescent ward
X49: Was the ward suitable for someone of your age?	Yes	67%	66%	80%
	Sort of	25%	24%	17%
	No	8%	9%	3%

Note: Percentages of children and young people aged 12 to 15 years who answered X5 and whose parents answered X49 (4,880).

The 2016 survey highlighted the small proportion of children staying on an adult ward for most of their hospital stay. The 2018 results show that this remains an area for improvement, with 1% of children aged 0 to 7 and 8 to 11 staying on an adult ward. Figure 11 shows that only a small proportion of young people aged 12 to 15 stayed on a teenage or adolescent ward (9%).

Figure 11. Response percentages for X5: For most of their stay in hospital, what type of ward did your child stay on? by age group



Note: Answered by parents and carers of all age groups. Number of respondents: parents of children aged 0 to 7 (23,120), 8 to 11 (4017) and 12 to 15 (4,654).

[Getting the right start: National Service Framework for Children](#) states that clinical equipment must be the correct size and tailored to an individual's age and stage of development. The hospital environment must also be spacious enough to accommodate the equipment required by children and young people with disabilities.¹⁵

Parents and carers of all age groups were asked 'Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?'. For all age groups combined, 82% said 'yes, definitely', 16% said 'yes, to some extent' and 3% said 'no'. However, results were significantly different for each parent group. As in 2016, parents of young people aged 12 to 15 were less positive (figure 12). For this age group, less than three-quarters (73%) said 'yes, definitely'.

Figure 12. Response percentages for X6: Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs? by age group

	Age group				Significant difference between:		
	0-7	8-11	12-15	0-15	0-7 & 8-11	0-7 & 12-15	8-11 & 12-15
Yes, definitely	83%	80%	73%	82%	*	*	*
Yes, to some extent	14%	17%	22%	16%	*	*	*
No	2%	3%	4%	3%	*	*	*

Note: Respondents who answered 'Don't know / can't remember' or 'They did not need equipment or adaptations' have been excluded. Number of respondents: parents of children aged 0 to 7 (19,233), 8 to 11 (3,083), 12 to 15 (3,360), 0 to 15 (25,675).

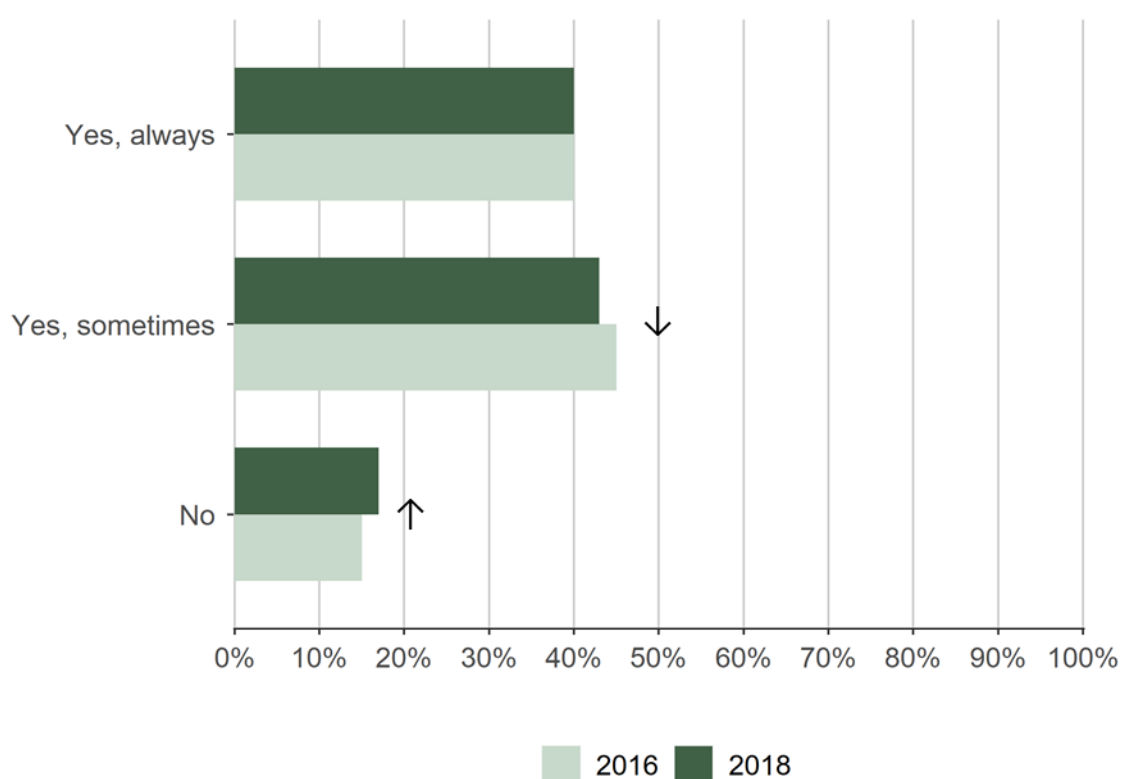
The subgroup analysis included a theme 'Respect for the child's individual needs and preferences', which was a composite of this question on appropriate equipment and adaptations and question X23: 'Did you feel that staff looking after you and your child knew how to care for their individual or special needs?'. Poorer than average experiences were reported by parents of children with a developmental disability, a mental health condition, a neurological condition, 'another long term condition', as well as those that stayed on an adult ward.

Research suggests that noise is a significant disruptor of sleep in hospitals and has negative consequences for well-being and experiences of care.^{56,57} The British Medical Association's report [The Psychological and Social Needs of Patients](#) stresses the benefit of quiet hospital environments for patient's functioning and their recovery from illness.⁵⁸ NHS Estate's [Improving the patient experience – Friendly healthcare environments for children and young people](#) highlights rest and sleep as a key consideration in the planning of care facilities and highlights the potential for noisy environments to cause distress by interrupting children and young people's sleep.⁵⁹ NHS England's [Toolkit's for reducing poor experiences of inpatient care](#) identifies night time disturbance as an area for improvement in the NHS and reports on several case studies of trusts that have managed to successfully reduce noise at night.⁵²

We asked children and young people whether it was quiet enough to sleep when they needed to. For children and young people aged 8 to 15 combined, findings were slightly poorer compared with 2016 (figure 13), with a small but statistically significant increase in the proportion of children reporting that it was not quiet enough for them to sleep. While in 2016 the figure was 15%, in 2018 it was 17%. Four in 10 (40%) children and young people thought it was ‘always’ quiet enough to sleep.

Young people aged to 12 to 15 were significantly less positive than children aged 8 to 11, with 38% of this age group reporting that it had ‘always’ been quiet enough to sleep compared with 43% of the younger age group.

Figure 13. Response percentages for X53: Was it quiet enough to sleep when needed in the hospital? by survey year



Note: Answered by children and young people aged 8 to 15 (2016 = 7,420; 2018 = 6,846). Children and young people who answered “I did not need to sleep in the hospital” are excluded. Arrows indicate statistically significant increase ↑ or decrease ↓ between 2016 and 2018

Privacy

Under the [NHS Constitution](#), patients have the right to privacy and confidentiality.⁶ This is reinforced in the [NHS Patient Experience Framework](#), which highlights the importance of respect for patient-centred values, preferences, and needs.² Both the DHSC’s [Getting the Right Start: National Service Framework for Children](#) and the WHO’s [Standard for improving the quality of care for children and young adolescents](#)

in health facilities acknowledge the specific importance of children and young people's need for privacy, and recognise that increasing the privacy and confidentiality of children as they develop and become more independent.^{15,44} Young people's rights to confidentiality and privacy in the NHS is also recognised in the NHS Youth Forum's [Youth Rights in Healthcare](#).²²

Children and young people aged 8 to 15 were asked 'Were you given enough privacy when you were receiving care and treatment?'. More than four in five children and young people said that they were 'always' (82%) given enough privacy, only a small proportion said 'no' (2%). Parents of children aged 0 to 7 were similarly positive: again, more than four in five (84%) said that their child was 'always' given enough privacy. Only a small proportion said 'no' (2%). Figures for both questions are not significantly different from 2016.

The National Children's Bureau's report [Children, Young People and Health Participation](#), states that children and young people want to have some control over their parents' or carers' involvement in their care, to vary the extent to which they are involved in decision making, and to have opportunities to talk alone with a health professional.⁶⁰ However, the 2012 Annual Report of the Chief Medical Officer, [Our Children Deserve Better: Prevention Pays](#), highlighted that it is often difficult for children and young people to discuss their care independently.⁶¹ The NHS Youth Forum's [Youth Rights in Healthcare](#) pledges a right to conversations that are 'private between you and a healthcare professional'.²² [You're Welcome - Quality criteria for young people friendly health services](#) states that young people should regularly have opportunities to be seen on their own.¹⁶

We asked young people aged 12 to 15 whether, if they wanted to, they were able to talk to a doctor or nurse without their parent or carer being there. Of those who indicated that they had wanted to talk to a nurse or doctor alone, 90% said they were able to and 10% (one in 10) said they were not able to. These proportions are not significantly different from 2016.

Cleanliness

The Health and Social Care Act 2008 [Code of Practice on the prevention and control of infections](#) states that good infection prevention, including cleanliness, is essential to the safe and effective care of people who use health and social care services.⁶²

The [Patient-Led Assessments of the Care Environment \(PLACE\)](#) annually assess the quality of the patient environment, including cleanliness.⁶³ NHS Digital publish national and local results of assessments to encourage improvement.⁶⁴

All parents were asked 'How clean do you think the hospital room or ward was that your child was in?'. As in 2016, 97% answered with either 'very clean' (67%) or 'quite clean' (30%).

3. Doctors and nurses

Communication with children and young people

As highlighted by the [NHS Patient Experience Framework](#), information, communication and education about clinical status, progress and processes of care are critical aspects of patient experience.² [You're Welcome - Quality criteria for young people friendly health services](#) requires all staff who are likely to interact with young people to have received training on communicating effectively with them.¹⁶ The National Children's Bureau's [Children, Young People and Health Participation](#) highlights that children and young people want to be communicated with in ways they can understand, and that interaction is tailored to their needs and capabilities.⁶⁰ [Getting the Right Start: National Service Framework for Children](#) asks that, to ensure that they can participate fully in their care, a range of communication methods should be used to share information with children.¹⁵

More than four in five children aged 8 to 15 (85%) said that hospital staff talked with them about how they were going to care for them, but figure 14 shows that young people aged 12 to 15 (87%) were significantly more positive than children aged 8 to 11 (83%). Overall, just over one in 10 said that staff had 'sort of' talked to them (12%) and a small percentage said 'no' (3%). For all age groups, this year's figures were not significantly different from those in 2016.

Figure 14. Response percentages for X54: Did hospital staff talk with you about how they were going to care for you? by age

	Age group			Significant difference between: 8-11 & 12-15
	8-11	12-15	8-15	
Yes	83%	87%	85%	*
Sort of	14%	11%	12%	*
No	3%	3%	3%	

Note: Number of respondents: children aged 8 to 11 (4,487), 12 to 15 (5,364), 8 to 15 (9,851).

Just under three in 10 (29%) children aged 8 to 15 said they did not 'always' understand staff when they spoke with them ('yes, sometimes' 28% and 'no' 2%). However, for children aged 8 to 15, results were more positive in 2018 than in 2016, with the most positive response 'yes, always' rising from 68% to 71% – a statistically significant increase. Children aged 8 to 11 were significantly less positive than young people aged 12 to 15.

Parents of children aged 0 to 7 were less positive about how staff communicated with their children: 65% said staff 'definitely' communicated with their child in a way they could understand, 26% said they did 'to some extent' and 9% said they did not.

Positively, most children and young people (95%) said that they felt able to ask staff questions and most children and young people said that staff answered their questions (92%). Fewer than 1% of children said that staff did not answer their questions. For both questions, figures are almost unchanged from 2016. Only one percentage change was statistically significant: a slightly larger proportion of children aged 8 to 11 said that hospital staff 'sort of' answered their questions in 2018 (8%) than in 2016 (7%).

Communication with parents and carers

In addition to communication with children and young people, we asked parents and carers questions about how staff had communicated with them. All parents were asked whether members of staff treating their child gave them information about their care and treatment in a way that they could understand. More than four in five (82%) said 'yes, definitely', 16% said 'yes, to some extent' and just 2% said 'no'.

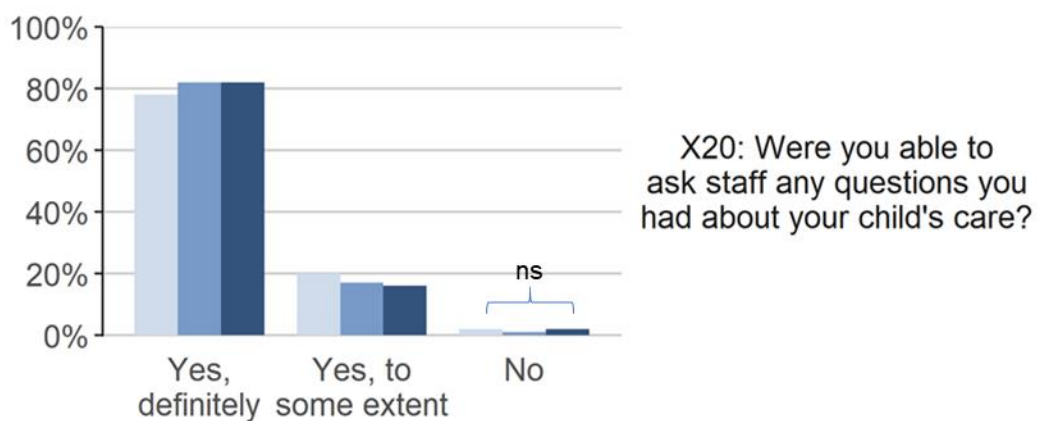
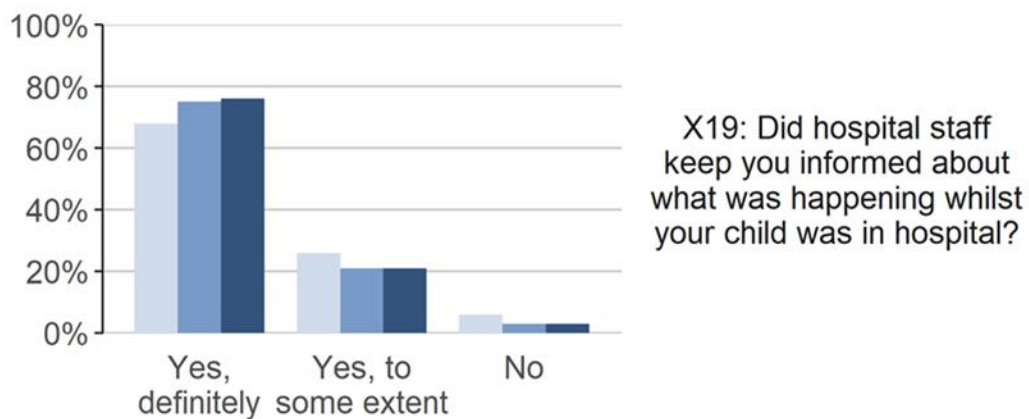
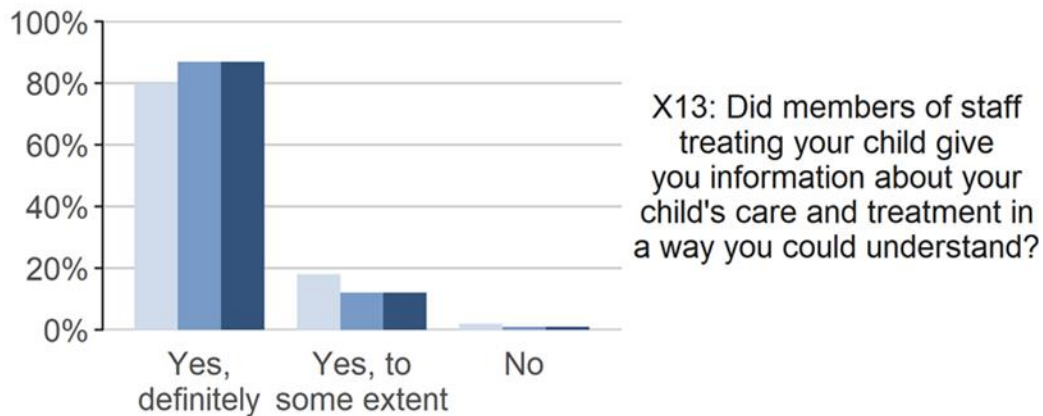
Parents were also asked whether they were able to ask staff any questions they had about their child's care. Just under four in five (79%) said 'yes, definitely', 19% said 'yes, to some extent' and just 2% said 'no'.

When asked whether staff kept them informed about what was happening while their child was in hospital, responses were less positive: seven in ten (70%) said 'yes, definitely', a quarter said 'yes, to some extent' (25%) and one in 20 said 'no' (5%).

Figure 15, below, shows that, for each of these questions, parents of children aged 0 to 7 were less positive than parents of children aged 8 to 11 and young people aged 12 to 15. All but one of the differences between parents of children aged 0 to 7 and each of the older parent groups are statistically significant (the percentage of parents of children aged 0 to 7 who said that they were not able to ask staff questions was not significantly different from the percentage of parents of children aged 12 to 15).

Parents of children aged 0 to 7 were also asked whether different staff gave them conflicting information. Of all questions on communication with parents and carers, results were poorest for this question. One in 10 (10%) said 'yes, a lot', just under a quarter said 'yes, sometimes' (24%) and two-thirds said 'no, never' (66%) (figure 16). These percentages are almost unchanged from 2016, but there is a small yet statistically significant increase in the proportion of parents who said 'yes, a lot' (up 1 percentage point from 9% in 2016).

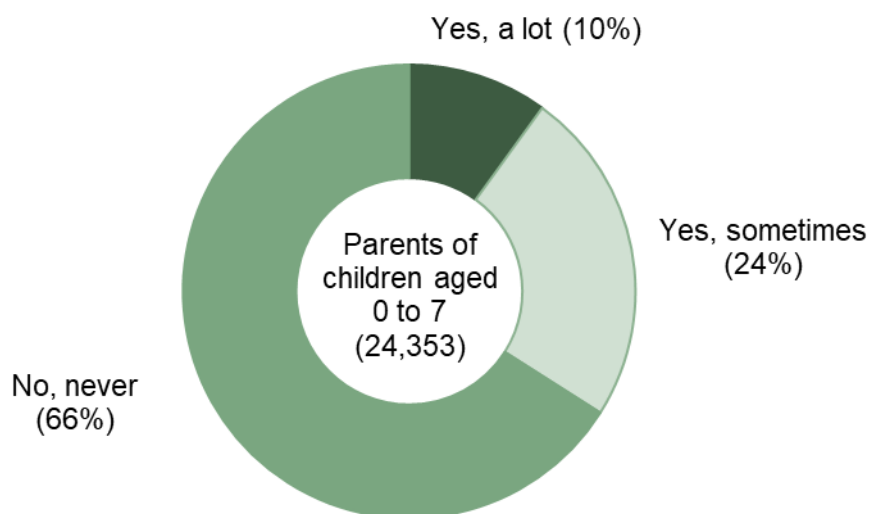
Figure 15. Response percentages for parents' communication questions by parent group



Parents of children aged 0-7 8-11 12-15

Note: Number of respondents for X13: 0-7 (23,882), 8-11 (4,177), 12-15 (4,875); X19: 0-7 (23,563), 8-11 (4,125), 12-15 (4,808); X20: 0-7 (23,538), 8-11 (4,113), 12-15 (4,763). ns = non-significant percentage difference.

Figure 16. Response percentages for X21: Did different staff give you conflicting information?



[You're Welcome - Quality criteria for young people friendly health services](#) requires staff to explain who they are and the services they are able to provide to children and young people.¹⁶ The [Hello my name is...](#) campaign emphasises how a simple introduction can be a crucial first step towards a positive therapeutic relationship between a patient and health care professional.⁶⁵

Parents and carers of children aged 0 to 7 were asked if members of staff introduced themselves. Just under four in five (79%) said 'yes, always', 18% said 'yes, sometimes' and just 4% said 'no'. These figures show small but statistically significant changes from 2016: in that year, 80% said 'yes, always', 17% said 'yes sometimes' and 3% said 'no'.

Involvement

The [NHS Constitution](#) pledges that, where appropriate, patients and their families will be involved in all decisions about their care and treatment.⁶ This is no less important for children. For example, [Getting the Right Start: National Service Framework for Children](#) recognises that children have a right to be involved in decisions under Article 12 of the [UN Convention for the Rights of the Child](#) and involving them in this way is key to child-friendly NHS services.¹⁵ Children and young people's rights, and desire, to be involved in care and treatment decisions is reiterated by both the National Children Bureau's [Children, Young People and Health Participation](#) and the NHS Youth Forum's [Youth Rights in Healthcare](#).^{60, 22}

The WHO's [Standards for improving the quality of care for children and young adolescents in health facilities](#) highlights children and young people's rights to active and meaningful participation in decisions about their care.⁴⁴ The King's Fund's [Making shared decision-making a reality: No decision about me, without me](#) states that shared decision making ensures that the clinician's and patient's complimentary expertise are combined so that decisions are made *with*, not for, the patient.⁶⁶

CQC's report [Better care in my hands](#) found that younger age groups were least likely to report being involved in their care.⁶⁷

One of only a few improvements in 2018, children and young people reported feeling more involved in their care in this survey than in 2016. The percentage of children aged 8 to 15 who felt they were involved 'a lot' increased from 43% in 2016 to 46% in 2018.

The improvement between years is most pronounced for children aged 8 to 11; 39% said they were involved 'a lot' in 2016 compared with 44% in 2018. However, figure 17 shows that, as in 2016, young people aged 12 to 15 felt more involved in their care than children aged 8 to 11.

Figure 17: Response percentages for X58: Were you involved in decisions about your care and treatment? by age

	Age group			Significant difference between: 8-11 & 12-15
	8-11	12-15	8-15	
Yes, a lot	44%	47%	46%	*
Yes, a little	39%	40%	39%	
No	17%	13%	15%	*

Number of respondents: children aged 8 to 11 (4,287), 12 to 15 (5,156), 8 to 15 (9,443). Respondents who answered 'I did not want to be involved' have been excluded.

We asked all parents three questions about their involvement in their child's care. Parents' responses were more positive than children and young people's when we asked them whether staff involved them in decisions about their child's care and treatment. Seven in 10 (70%) said that they were 'definitely' involved, while one in 20 said 'no' (5%; compared with three in 20 children and young people).

Just over three quarters of all parents (76%) said they were 'definitely' given enough information to be involved in decisions about their child's care and treatment. Less than one in 20 (4%) said they were not. Figure 18, below, shows that the parents of children aged 0 to 7 were less positive than other parent groups. Most parents (91%) said that staff had agreed a plan for their child's care with them, but almost one in 10 did not (9%).

Figure 18. Response percentages for X18: Were you given enough information to be involved in decisions about your child's care and treatment? by parent group

	Age group				Significant difference between:		
	0-7	8-11	12-15	0-15	0-7 & 8-11	0-7 & 12-15	8-11 & 12-15
Yes, definitely	74%	80%	80%	76%	*	*	
Yes, to some extent	22%	17%	17%	20%	*	*	
No	4%	2%	2%	4%	*	*	

Note: Number of respondents: parents of children aged 0 to 7 (23,606) 8 to 11 (4,138), 12 to 15 (4,832), 0 to 15 (32,557).

Knowledge

We asked all parents 'Were the different members of staff caring for and treating your child aware of their medical history?'. Although the majority felt staff were aware (58%), more than four in 10 parents did not choose 'yes, definitely', choosing either 'yes, to some extent' (33%) or 'no' (8%) instead. Figure 19 shows that parents of children aged 0 to 7 were the most negative of the parent groups.

Figure 19: Response percentages for X22: Were the different members of staff caring for and treating your child aware of their medical history? by age

	Age group				Significant difference between:		
	0-7	8-11	12-15	0-15	0-7 & 8-11	0-7 & 12-15	8-11 & 12-15
Yes, definitely	55%	66%	65%	58%	*	*	
Yes, to some extent	35%	28%	29%	33%	*	*	
No	9%	6%	6%	8%	*	*	

Note: Number of respondents: parents of children aged 0 to 7 (20,533), 8 to 11 (3,750), 12 to 15 (4,348), 0 to 15 (28,630). Respondents who answered 'Don't know / not applicable' have been excluded.

All parents were also asked whether they felt that staff looking after their child knew how to care for their individual or special needs. As in 2016, more than a quarter of parents felt that staff did not 'definitely' know how to care for their child's individual or special needs ('yes, to some extent' 24% and 'no' 4%).

Figure 20 shows that parents and carers of children with a long-term physical or mental health condition were less positive than those with children without a long-term condition. While almost eight in 10 parents of children without a long-term condition (78%) said staff 'definitely' knew how to care for their individual or special needs, the figure was six in 10 for parents of children with a long-term condition (60%).

Figure 20. Response percentages for X23: Did you feel that staff looking after your child knew how to care for their individual or special needs? by X76: Does your child have any physical or mental health conditions that have lasted or are expected to last 12 months or more?

		Does your child have any physical or mental health conditions that have lasted or are expected to last 12 months or more?		Significant difference
		Yes	No	
X23: Do you feel that staff looking after your child knew how to care for their individual or special needs?	Yes, definitely	60%	77%	*
	Yes, to some extent	32%	20%	*
	No	8%	3%	*

Note: Answered by parents of children aged 0 to 15 who answered both questions (25,750).

Support

The [NHS Patient Experience Framework](#) highlights emotional support, and the alleviation of worries and fear, as a key aspect of patient experience.² Quality statement 4, Individualised Care, of the NICE guideline [Patient experience in adult NHS services](#) also states that people should be able to discuss their concerns with those caring for them.¹⁹

Specifically relating to the care of children and young people, Standard 6 of the WHO's [Standards for improving the quality of care for children and young adolescents in health facilities](#) states that emotional and psychological support is important from a child's admission to their discharge.⁴⁴ According to the NICE guideline [Transition from children's to adults' services for young people using health or social care services](#) a person-centred approach that includes attention to emotional health is particularly relevant for young people who are beginning the transition to adult healthcare services.⁴⁵

Children and young people aged 8 to 15 were asked whether, if they had any worries, a member of staff had talked with them about them. Of the children and young people who had worries, more than nine in 10 (92%) said 'yes' (8% said 'no'). Figure 21, below, shows that young people aged 12 to 15 were more positive than children aged 8 to 11.

Figure 21: Response percentages for X59: If you had any worries, did a member of staff talk with you about them? by age

	Age group			Significant difference between: 8-11 & 12-15
	8-11	12-15	8-15	
Yes	90%	94%	92%	*
No	10%	6%	8%	*

Note: Number of respondents: children aged 8 to 11 (2,966), 12 to 15 (3,354), 8 to 15 (6,320). Respondents who answered 'I did not have any worries' or 'I did not want to talk to staff' have been excluded

Availability and teamwork

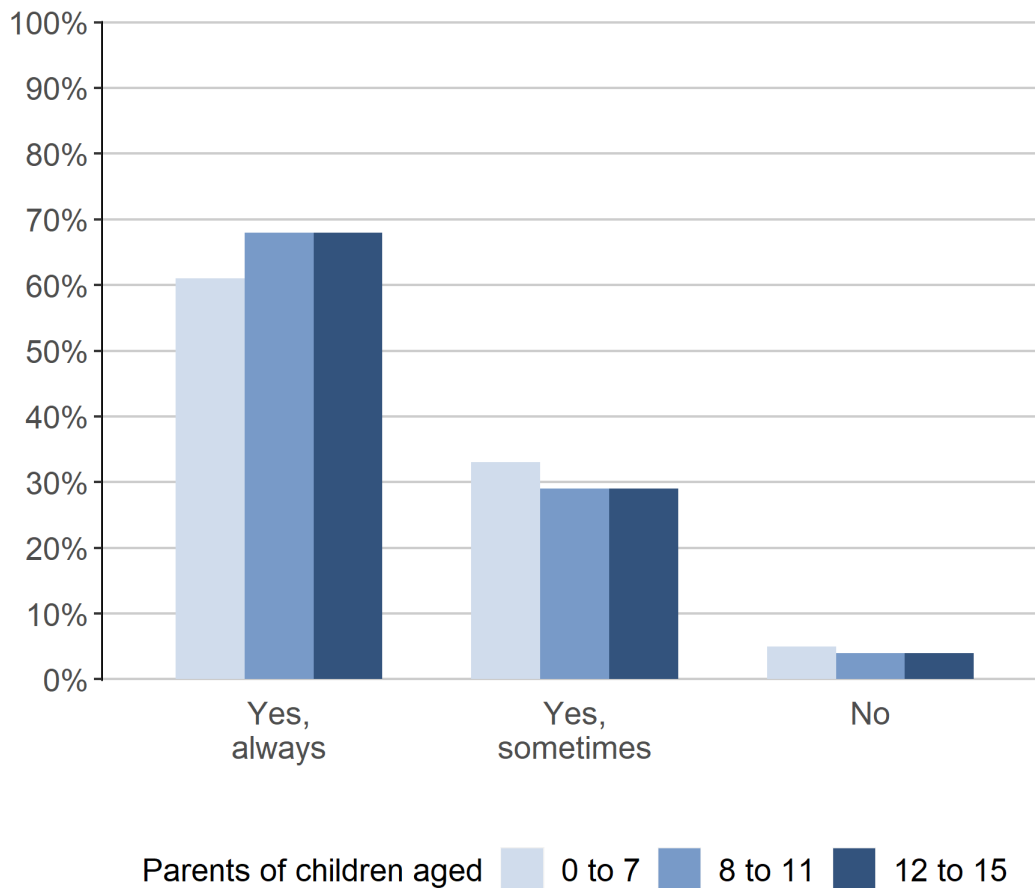
The National Quality Board's [Safe, sustainable and productive staffing: An improvement resource for children and young people's inpatient wards in acute hospitals](#) states that 'children and young people's inpatient wards must have sufficient and appropriate staffing capacity and capability to provide safe, high-quality and cost-effective care at all times'. Moreover, annual evidence-based reviews of staffing should consider feedback on staffing from children, young people and their parents.⁶⁸

The Royal College of Nursing's [Defining staffing levels for children and young people's services](#) set out the numbers of nurses expected for each patient for both general and specialist children's wards, including a minimum of two registered children's nurses in inpatient and day case areas and increasing staff to patient ratios.³⁹ The Royal College of Paediatrics and Child Health's [Facing the Future: Standards for Acute General Paediatric Services](#) stresses that there must be sufficient staff to deliver the standards, such as every admitted child being seen by a consultant paediatrician within 14 hours of admission.⁶⁹

All parents were asked whether members of staff were available when their child needed attention. As in 2016, over a third of parents did not think that staff were 'always' available when their child needed attention: over three in 10 said they were 'sometimes' available (32%) and 5% said that they were not available. As in 2016, parents and carers of children aged 0 to 7 were significantly more negative than the parents of older children (see figure 22).

When asked if all members of staff worked well together, 76% of parents said 'yes, definitely', 21% of parents said 'yes, to some extent' and 3% said 'no'.

Figure 22. Response percentages for X24: Were members of staff available when your child needed attention? by age group



Note: Respondent numbers: parents of children aged 0 to 7 (22,486), 8 to 11 (4,018), 12 to 15 (4,633).

Confidence

All parents were asked whether they had confidence and trust in the members of staff who treated their child. Overall, 80% said 'yes, always', 18% said 'yes, sometimes', and a small proportion said 'no' (3%). Figure 23, below, shows that parents of children aged 0 to 7 were the least positive. While 78% of this group of parents said 'yes, always', the figure was 84% for parents of children aged 8 to 11 and 12 to 15.

Figure 23. Response percentages for X16: Did you have confidence and trust in the members of staff treating your child? by parent group

	Age group				Significant difference between:		
	0-7	8-11	12-15	0-15	0-7 & 8-11	0-7 & 12-15	8-11 & 12-15
Yes, always	78%	84%	84%	80%	*	*	
Yes, sometimes	19%	15%	14%	18%	*	*	
No	3%	2%	2%	3%	*	*	

Note: Respondent numbers: parents of children aged 0 to 7 (23,860), 8 to 11 (4,176), 12 to 15 (4,864) and 0 to 15 (32,900).

Raising concerns

The [NHS Constitution](#) gives people, both patients and staff, the right to raise complaints or concerns and have their complaints or concerns addressed promptly.⁶ The constitution also pledges that staff should aim to be open, welcoming and listen to feedback from patients and their families. CQC research suggests that many people who have concerns about their health and social care do not raise them.⁷⁰ CQC's [Declare Your Care](#) campaign is encouraging people to speak up about their care experiences.

All parents were asked 'If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?'. Figure 24 shows that, overall, just under two-thirds said 'yes, always' (64%), a quarter said 'yes, sometimes' (25%) and one in 10 (10%) said 'no'.

Figure 24. Response percentages for X26: If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff? by parent group

	Age group				Significant difference between:		
	0-7	8-11	12-15	0-15	0-7 & 8-11	0-7 & 12-15	8-11 & 12-15
Yes, always	62%	70%	72%	64%	*	*	*
Yes, sometimes	27%	23%	21%	25%	*	*	
No	12%	8%	7%	10%	*	*	

Note: Respondent numbers: parents of children aged 0 to 7 (23,695), 8 to 11(4,138), 12 to 15 (4,814) and 0 to 15 (32,647).

4. Facilities for parents and carers

[Getting the Right Start: The National Service Framework for Children](#) states that hospitals should feature facilities for patients' parents and siblings, including overnight facilities, and that they should be able to access meals.¹⁵ Standard 8 of the [WHO Standards for improving the quality of care for children and young adolescents](#)

in health facilities also states that parents or caregivers should be able to stay with their children and sleep, wash, and cook.⁴⁴

We asked all parents whether they had access to hot drinks facilities in hospital (figure 25). Overall, around one in five (17%) said 'no', a statistically significant increase from 2016 (15%).

As in 2016, a significantly larger percentage of parents and carers of children aged 0 to 7 said 'no' (18%) than parents and carers of children aged 8 to 11 (14%) and parents and carer of young people aged 8 to 15 (11%). However, parents of children aged 0 to 7 were significantly more likely to have been offered drinks by staff (24% versus 20% and 21%, respectively).

Figure 25. Response percentages for X28: Did you have access to hot drinks facilities in the hospital? by parent group

	Age group				Significant difference between:		
	0-7	8-11	12-15	0-15	0-7 & 8-11	0-7 & 12-15	8-11 & 12-15
I used a kitchen area / parents room attached to the ward	54%	52%	54%	54%	*		
I used a hospital café / vending machine	33%	43%	45%	36%	*	*	
I was allowed to use the staff room	1%	1%	2%	1%			
I was offered drinks by members of staff	24%	20%	21%	23%	*	*	
I did not have access to hot drinks facilities in the hospital	18%	14%	11%	17%	*	*	*

Note: Number of respondents: parents of children aged 0 to 7 (23,357), 8 to 11 (4,096), 12 to 15 (4,771), 0 to 15 (32,225)

Over a third of parents and carers who had wanted to prepare food in hospital reported that they were unable to (36%). However, this figure is significantly lower than in 2016 (38%). Fewer than four in 10 said they were 'definitely' able to prepare food (39%).

Experiences of parents and carers who stayed overnight were more positive, as 66% rated the overnight facilities 'good', or 'very good'. Still, almost one in 10 rated the overnight facilities 'poor' (7%) or 'very poor' (2%).

5. Pain management

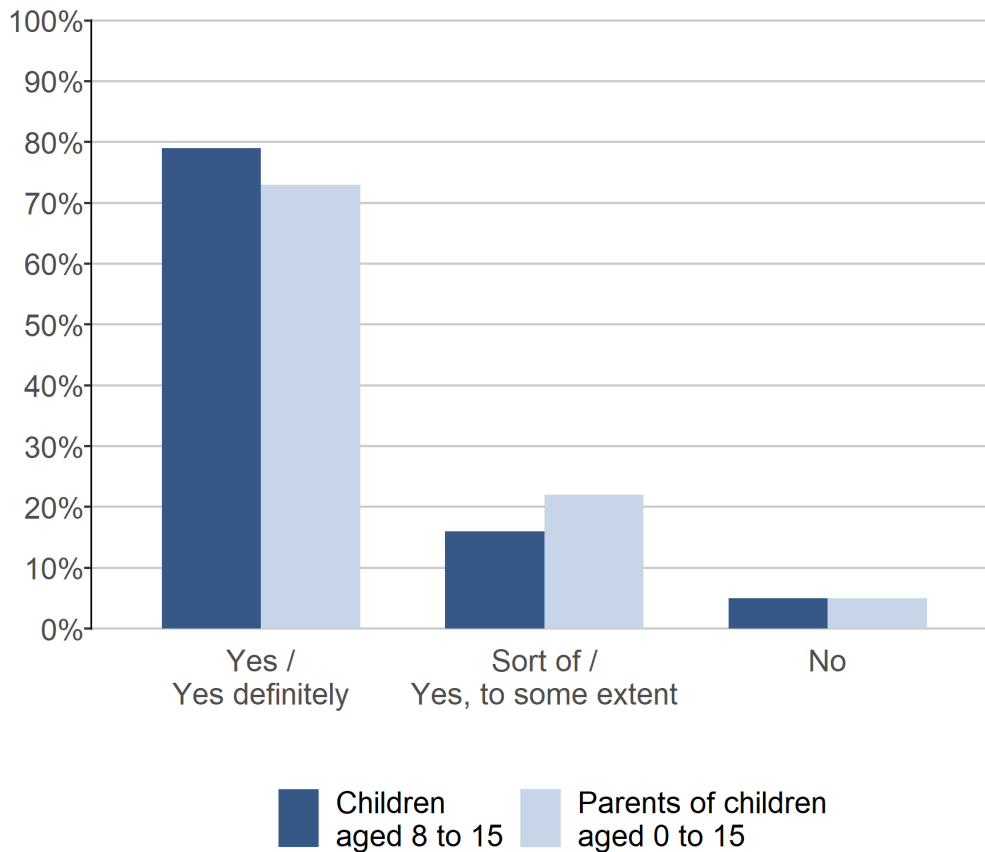
The [NHS Patient Experience Framework](#) highlights physical comfort, including the management of pain, as a key element of patient experience.² [Getting the Right Start: National Service Framework for Children](#) identifies pain management as an area for improvement in children's hospital care, and that both predictable (for example, following an operation or procedure) and unexpected pain should be assessed and then controlled with medicines or psychological therapies. Particular attention should be paid to the pain management of children and young people who have been admitted in an emergency, have long-term pain, and have had an operation or procedure.¹⁵

This is reinforced in the College of Emergency Medicine's best practice guidelines [Management of Pain in Children](#), which recommends that, from triage, pain management should be a priority in the care of children.⁷¹ [Postoperative pain management in children: Guidance from the pain committee of the European Society for Paediatric Anaesthesiology \(ESPA Pain Management Ladder Initiative\)](#) also highlights the importance of the assessment and re-evaluation of children's post-operative pain and provides recommendations for common procedures.⁷²

Children and young people aged 8 to 15 were asked 'If you felt pain while you were at the hospital, do you think staff did everything they could to help you?'. Of those children who reported that they had felt pain, 79% said 'yes', 16% said 'sort of' and 5% said 'no'.

Just over a quarter (27%) of parents of children aged 0 to 15, who reported their child felt pain, did not say staff 'definitely' did everything they could to help. Parents' views of pain management are compared with children and young people's in figure 26.

Figure 26. Response percentages for X62: If you felt pain while you were in the hospital, do you think staff did everything they could to help you? and X32: If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?



Note: Answered by children aged 8 to 15 (8,119) and parents of children aged 0 to 15 (24,910). For X62, respondents who answered 'I did not feel any pain' have been excluded. For X32, respondents who answered 'My child did not feel any pain' have been excluded.

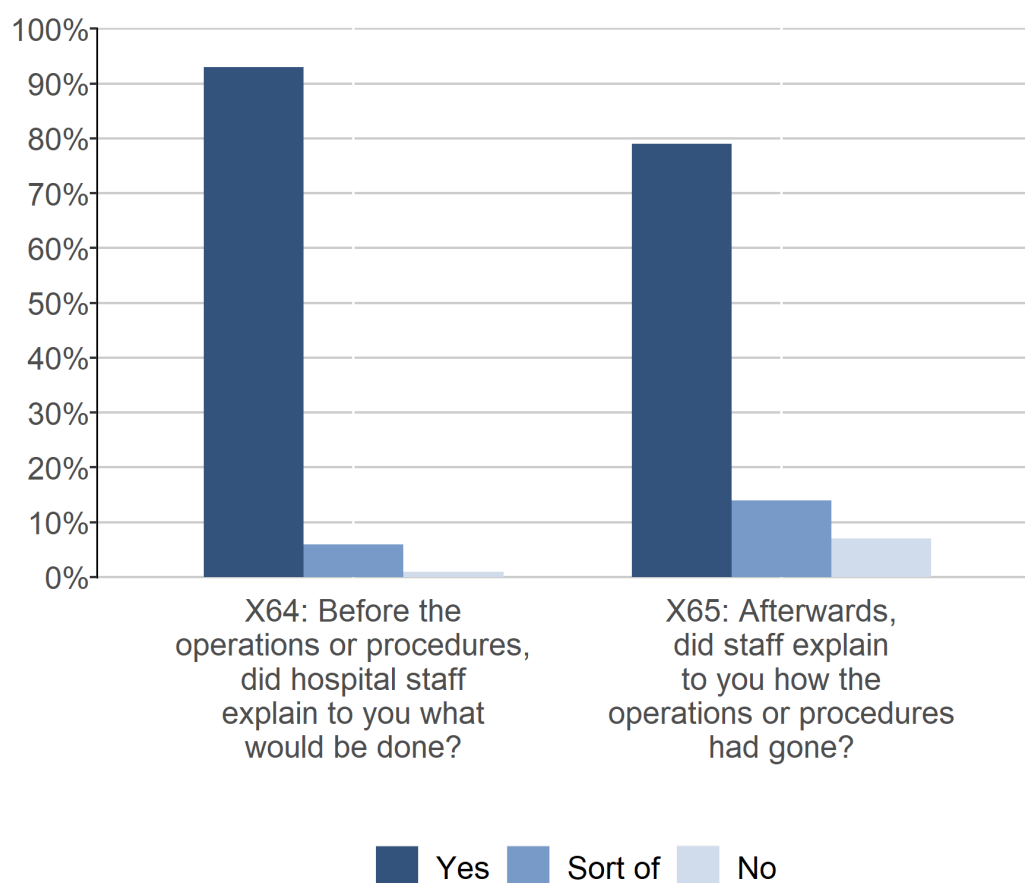
6. Operations and procedures

The Royal College of Surgeons' [Standards for Children's Surgery](#) recommends that both the child and their family are involved in the decision to operate.⁷³ Staff should frequently communicate with parents and, when they do, they should be given understandable information about their child's operation. Children and families should be able to discuss, for example, treatment options, findings, recovery timescales, and complications. The WHO's [Standards for improving the quality of care for children and young adolescents in health facilities](#) states that children and their families should be informed about proposed investigations, the risks and benefits, and that consent should be sought for procedures.⁴⁴ [Getting the Right Start: National Service Framework for Children](#) says that candid communication and information is especially important when a procedure is unpleasant or painful.¹⁵

Children and young people aged 8 to 15 who had an operation or procedure were asked two questions about their experiences (see figure 27). On communication before procedures, more than nine in 10 (93%) said 'yes', that staff explained the operation or procedure, around one in 20 said 'sort of' (6%) and very small proportion said 'no' (1%). In contrast, on communication after procedures, a comparatively smaller proportion (79%) said 'yes', that staff had explained how the operations or procedures had gone, a larger proportion said 'sort of' (14%) and over one in 20 (compared with one in 100) said 'no' (7%).

A similar pattern of results emerged for parents, with responses more positive for communication before operations and procedures than after. Whereas ninety per cent of parents said that staff had 'completely' explained what would be done before the operation or procedure, 79% felt that staff had 'completely' explained how the operation or procedure had gone.

Figure 27. Response percentages for operations and procedures questions for children and young people aged 8 to 15



Note: Answered by children and young people aged 8 to 15 (X64 = 6,447; X65 = 6,431)

The majority of parents (90%) whose child had an operation or procedure said that staff had 'completely' answered their questions about their child's operation or procedure in a way that they could understand. Fewer than one in 10 said that staff had answered their questions in a way they could understand 'to some extent' (9%) and just 1% said that that staff had not answered their questions in a way they could understand.

The Royal College of Surgeons' recommends that play specialists are available to distract and help children cope with procedures.⁷⁴ [Getting the Right Start: National Service Framework for Children](#) highlights the positive effects of play on children's ability to cope with procedures and interventions.¹⁵ The WHO's [Standards for improving the quality of care for children and young adolescents in health facilities](#) states that 'play should be used routinely to alleviate anxiety and stress, to enable children to cope with pain and to help in the management and outcomes of procedures'.⁴⁴

All parents were asked whether, during any operations or procedures, staff played with their child or distracted them. Over one in 10 said 'no' (12%), almost a quarter said 'yes, to some extent' (24%) and under two thirds said 'yes definitely' (64%). Responses were more positive for parents and carers of children aged 0 to 7 than other age groups: 66% said their child was distracted during operations or procedures, compared with 61% of parents of children aged 8 to 11 and 60% of parents of children aged 12 to 15.

7. Leaving hospital

The [NHS Patient Experience Framework](#) highlights transition and continuity, including information that will help people care for themselves after discharge, as a key element of patient experience.² [Getting the Right Start: National Service Framework for Children](#) states that, at the end of a hospital stay, children, young people and their parents should be given information about the possible after effects of treatments, any further treatment that may be required, medicines, and implications for school attendance.¹⁵ A point of contact should be provided in case of future difficulties. The comprehensiveness of this briefing should increase with increasing complexity of needs.

The Royal College of Surgeons' [Standards for Children's Surgery](#) asks that patients and their families receive clear information on discharge and that they are able to contact a health professional for support after leaving the hospital.⁷³ The DHSC's [Ready to Go? Planning the discharge and the transfer of patients from hospital and intermediate care](#) highlights the importance of communication with patients and their families before they leave the hospital, as well as their involvement in and agreement on decisions on their departure.⁷⁵

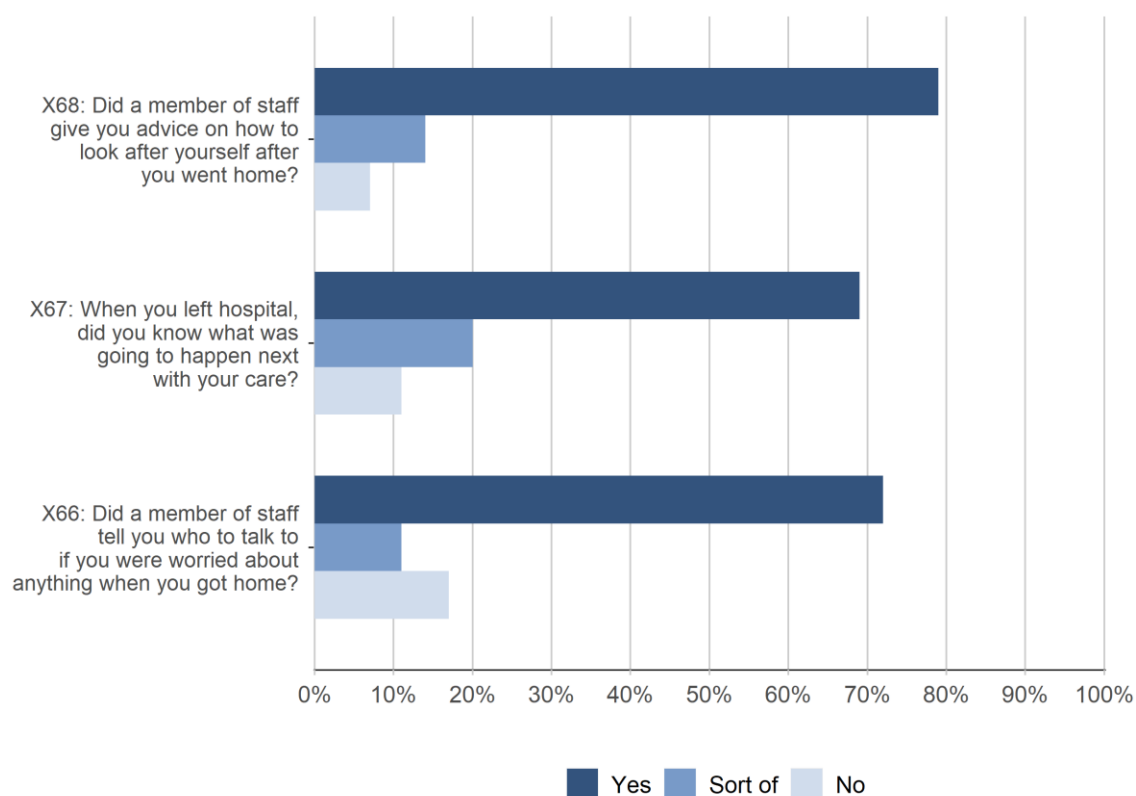
Children and young people aged 8 to 15 were asked three questions about their experience of leaving hospital (see figure 28). Around three quarters of children said that a member of staff gave them advice on how to look after themselves at home (79%), that they knew what was going to happen next with their care (69%) and that staff had told them who to talk to if they were worried when they got home (72%). The largest proportion of negative responses across this set of questions, 17% of children and young people said they were not told who to talk to if they were worried at home. Percentages for these questions were not significantly different from 2016.

Within these overall figures, for two of the questions related to leaving hospital, children aged 8 to 11 were significantly less positive than children aged 12 to 15. They were less likely to say they knew what was going to happen next with their care (8 to 11: 68% compared with 12 to 15: 71%) and that staff had told them who to talk to if they were worried at home (8 to 11: 70% compared with 12 to 15: 73%).

Similar to the findings for children, around three quarters of parents of children aged 0 to 15 said that a staff member gave them advice about caring for their child when they got home (78%) and had told them what was going to happen next with their child's care (71%). Both figures were significantly higher than in 2016, where they were 76% and 69%, respectively. Most parents of children aged 0 to 7 said that staff had told them who to talk to if they were worried about their child when they got home (79%).

Four in five parents of children aged 0 to 15 (80%), who said that they would have liked written information about their child's condition or treatment received this; one in five (20%) did not.

Figure 28. Response percentages for children and young people's questions on information when leaving hospital



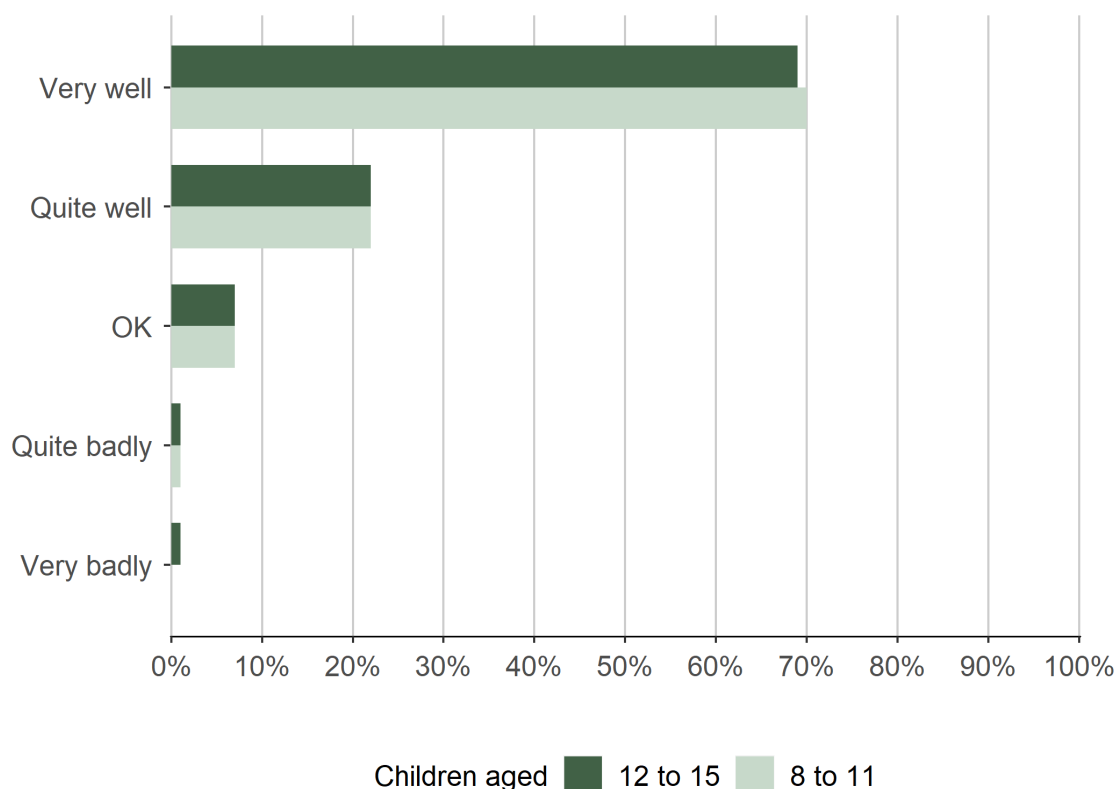
Note: Answered by children aged 8 to 15: X68 (9,364), X67 (10,089) and X66 (8,557). For X68, respondents who answered 'I did not need any advice' have been excluded.

8. Overall

Children and young people aged 8 to 15, as well as parents and carers of children aged 0 to 7, were positive when asked whether they thought staff were friendly. Most children and young people (87%) said that staff were friendly and most parents and carers (81%) said that staff were 'always' friendly. However, this figure for parents is significantly lower than in 2016, where it was 83%. As in 2016, just one in 100 (1%) in each group said that staff were not friendly.

Children and young people aged 8 to 15, as well as parents and carers of children aged 0 to 7, were similarly positive about how well they or their child were looked after in hospital. Most children (91%) said that they were 'quite' or 'very' well looked after (figure 29). Most parents (82%) said their child was 'always' well looked after by hospital staff. Just two in 100 (2%) children and young people said they were 'quite' or 'very' badly looked after. Similarly, just two in 100 (2%) parents said that their child was not well looked after by hospital staff.

Figure 29. Response percentages for X70: Overall, how well do you think you were looked after in hospital? by age



Note: Answered by children and young people aged 8 to 11 (4,640) and 12 to 15 (5,478).

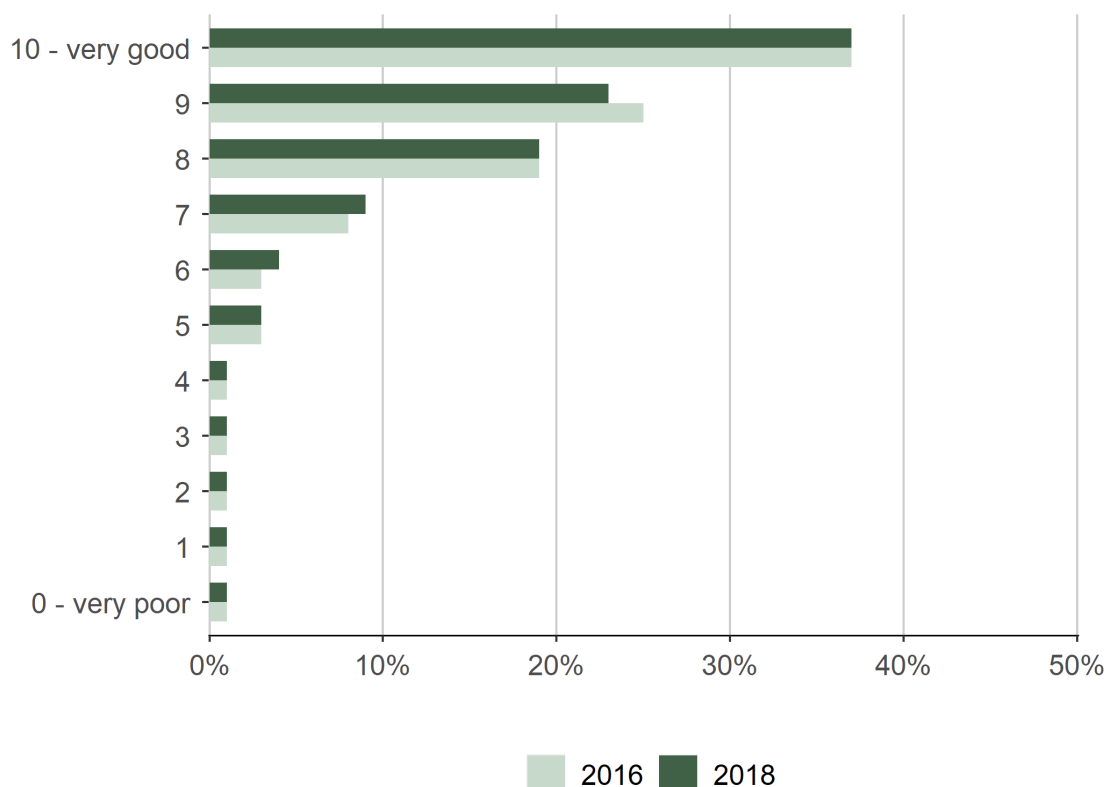
Parents were less positive about their own experiences than their child's. More than a quarter (27%) said they had 'sometimes' been well looked after and more than one in 20 (7%) said they had not been well looked after.

All parents and carers rated their child's care overall, on a scale from 0 'I felt that my child had a very poor experience' to 10 'I felt that my child had a very good experience'. Most (80%) rated their child's experience eight or above. Figure 30 shows responses are largely unchanged from 2016. One difference, the proportion of parents who selected 9 out of 10, was statistically significant (decreasing from 25% in 2016 to 23% in 2018).

Within these overall percentages, this year there were statistically significant increases in the most positive, 10 out of 10 ratings for parents of children aged 8 to

11 (2016 = 39%; 2018 = 43%) and 12 to 15 (2016 = 37%; 2018 = 40%). Figure 31 displays response percentages for this question by age group.

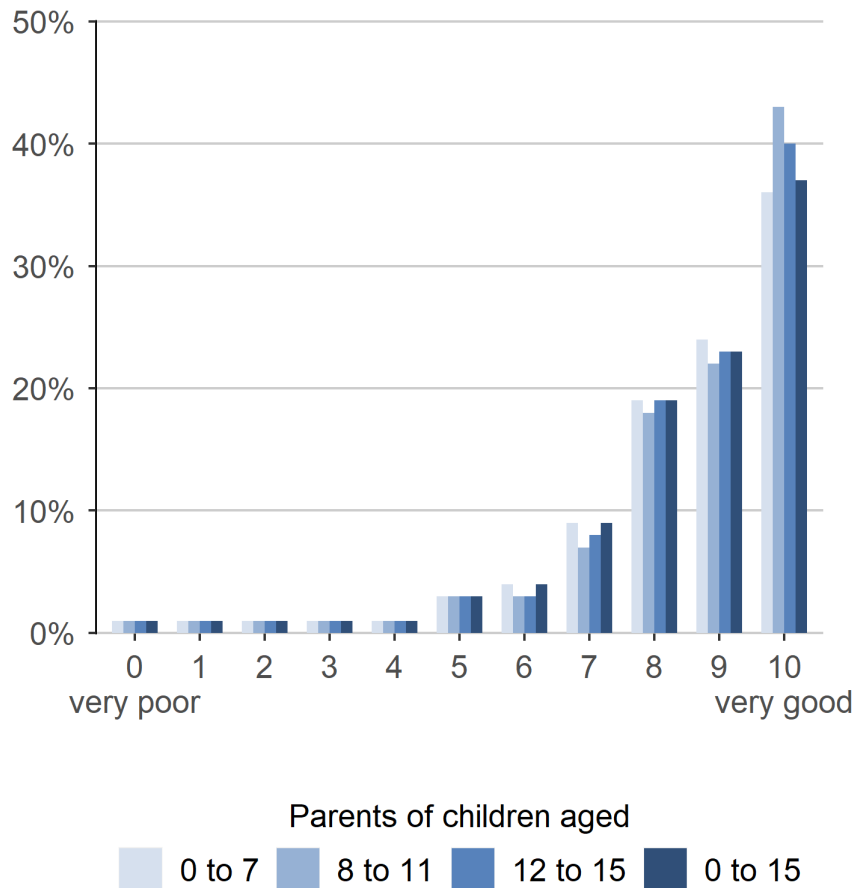
Figure 30. Response percentage for X47: Overall... I felt that my child had a very poor experience (0) to I felt that my child a very good experience (10) by year



Note: Answered by parents and carers of children aged 0 to 15 (2018 = 32,184, 2016 = 33,647).

All parents were asked whether they were treated with dignity and respect by the people looking after their child. Just two in 100 said 'no' (2%), a small proportion said 'yes, sometimes' (12%) and most said 'yes, always' (86%). Figure 32, below, shows that parents of children aged 0 to 7 reported significantly poorer experiences than parents of other age groups.

Figure 31. 2018 response percentage for X47: Overall... I felt that my child had a very poor experience (0) to I felt that my child a very good experience (10) by age group



Note: Number of respondents: parents of children aged 0 to 7 (23,311), 8 to 11 (4,101), 12 to 15 (4,772) and 0 to 15 (32,184).

Figure 32: Response percentages for X46: Were you treated with dignity and respect by the people looking after your child? by parent group

	Age group				Significant difference between:		
	0-7	8-11	12-15	0-15	0-7 & 8-11	0-7 & 12-15	8-11 & 12-15
Yes, always	85%	89%	89%	86%	*	*	
Yes, sometimes	13%	10%	10%	12%	*	*	
No	2%	1%	1%	2%	*	*	

Note: Number of respondents: parents of children aged 0 to 7 (23,757) 8 to 11 (4,172), 12 to 15 (4,843) and 0 to 15 (32,772)

9. How experience varies for different patient groups: subgroup analysis summary

We have included additional analysis to compare how different subgroups of patients rated their hospital experiences. Using a multi-level model, we have compared different groups' mean scores for a subset of questions. This technique takes account of interdependencies between variables.

There is separate subgroup analysis for children and young people aged 8 to 15 and for parents and carers of children and young people aged 0 to 15. The following themes were assessed, with most based on the [Patient Experience Framework](#).

Children and young people aged 8 to 15:

- **Information and communication**
 - X54: Did hospital staff talk with you about how they were going to care for you?
 - X55: When the hospital staff spoke with you, did you understand what they said?
 - X57: Did the hospital staff answer your questions?
- **Transition and continuity**
 - X67: When you left hospital, did you know what was going to happen next with your care?
 - X68: Did a member of staff give you advice on how to look after yourself after you went home?
- **Respect for patient centred values, preferences and expressed needs**
 - X58: Were you involved in decisions about your care and treatment?
 - X60: Were you given enough privacy when you were receiving care and treatment?
- **Food** (X52: Did you like the hospital food?)
- **Activities** (X50: Were there enough things for you to do in the hospital?)
- **Emotional support** (worries) (X59: If you had any worries, did a member of staff talk with you about them?)
- **Children feeling well looked after** (X70: Overall, how well do you think you were looked after in hospital?).

Parents and carers of children and young people aged 0 to 15:

- **Welcoming the involvement of family and friends**
 - X15: Did a member of staff agree a plan for your child's care with you?
 - X17: Did staff involve you in decisions about your child's care and treatment?
 - X20: Were you able to ask staff any questions you had about your child's care?
- **Respect for their child's individual needs and preferences**

- X6: Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?
- X23: Did you feel that staff looking after you and your child knew how to care for their individual or special needs?
- **Confidence and trust** (X16: Did you have confidence and trust in the members of staff treating your child?)
- **Dignity and respect** (X46: Were you treated with dignity and respect by the people looking after your child?)
- **Awareness of medical history** (X22: Were the different members of staff caring for and treating your child aware of their medical history?)
- **Feeling able to raise concerns** (X26: If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?)
- **Parents feeling well looked after** (X45: Do you feel that you (the parent/carer) were well looked after by hospital staff?)
- **Children's overall experience** (X47: Overall... I felt that my child had a very poor experience (0) to I felt that my child had a very good experience (10)).

For a table that maps scored question IDs (for example, X54) to question text and question numbers in each of the three questionnaires please see [appendix G](#). See the detailed charts for the subgroup analyses in [appendix F](#).

For more information about the subgroup analysis, criteria for noteworthy subgroup differences, and methodology see the [survey methodology](#) section.

Age

Experiences did not differ by age.

Gender

Experiences did not differ by gender.

Ethnicity

Parents and carers of Asian children reported poorer experiences of feeling able to raise concerns. Parents and carers of Black children reported poorer experiences on feeling that they, as a parent, had been well looked after.

Long-term conditions

Children and young people who had cancer in the last five years reported poorer perceptions of hospital food. This finding may be linked to taste and smell changes, which research shows are common during cancer treatment.⁷⁶

Parents and carers with a child with a self-reported mental health condition had notably poorer experiences on the 'welcoming the involvement of family and friends' theme and had significantly poorer perceptions of their child's overall care experience.

Parents and carers who reported their child has a developmental disability, such as Autism Spectrum Disorder (ASD), a mental health condition, a neurological condition such as epilepsy, or 'another long-term condition', reported more negative experiences on the 'respect for their child's individual preferences and needs' theme.

Parents and carers of children who had cancer in the last five years reported more positive experiences on the 'awareness of medical history' theme.

Proxy response

There were no differences in experiences when comparing whether children and young people completed their section of the questionnaire by themselves, their parent/carer completed on their behalf, or both the child/young person and the parent/care completed it jointly.

Medical care vs surgical treatment

Experiences did not differ by medical or surgical care and treatment.

Overnight stay vs no overnight stay

Experiences did not differ by whether the child or young person stayed overnight or did not stay overnight.

Number of hospital stays in past six months

Experiences did not differ by the number of times the child or young person had been to hospital in the previous six months.

Type of ward stayed on

Where a child or young person had stayed on an adult ward, experiences were more negative in two areas. First, children and young people reported worse than average experiences for there being 'enough things to do' when treated on an adult ward. Second, parents and carers reported poorer than average experiences for 'respect for their child's individual needs and preferences'.

Survey methodology

As is currently standard for the NHS Patient Survey Programme, the 2018 Children and young people's patient experience survey used a postal methodology. Each sampled patient received a maximum of three mailings. A paper questionnaire was sent in both an initial mailing and a second reminder mailing.

Patients aged 15 days to 15 years at the time of discharge were eligible to participate in the survey. The survey sample did not include babies aged 0 to 14 days to reduce the likelihood of including 'well babies' who were born in an NHS trust and whose mothers had been the patient.

Trusts were required to draw a stratified sample of up to 1,250 eligible patients from their records who attended hospital as an inpatient or day case and were discharged during November and December 2018.^b Sample size targets were set at 450 for patients aged 0 to 7 and 400 each for those aged 8 to 11 and 12 to 15. The slightly higher target for those aged 0 to 7 reflects a lower average response rate for this group in the 2014 and 2016 survey. The target for the 8 to 11 and 12 to 15 was to oversample these age groups to allow analysis at a trust level. Any trust unable to meet the sampling targets was permitted to 'top-up' with eligible patients from any other age group, where possible. The possible over-representation of those aged 8 to 15 in the national results has been accounted for within the weighting method applied.

Full details of the sampling are available in the instruction manual for the survey (see the links in [appendix E](#)).

Eligible trusts were those that provided acute hospital care to sufficient numbers of children and young people to draw a sample. No trusts were excluded from the survey.

Fieldwork for the survey (the time during which questionnaires were sent out and returned) took place between February and June 2019.

Analysis methodology

Weighting

We used a two-stage weighting approach to:

- account for the over-sampling of children and young people aged 8 to 15
- to aggregate trust-level data to national level.

The first element is referred to as the 'population weight', where trust responses were weighted to reproduce the population age structure for that trust. This ensures

b. Five trusts were permitted to sample patients discharged in October 2018. Just 172 respondents (0.5%) were discharged in October.

that the responses from those aged 0 to 7, 8 to 11 and 12 to 15 have the appropriate influence on national results to reflect the numbers of children within each age group admitted to hospital.

The second element of the weighting is referred to as the 'trust weight' and has been calculated to give each participating trust an equal influence within national results, regardless of differences in response rates between trusts.

Both sets of weights are then multiplied together to produce a single combined weight for the data tables that underpin the analysis.

Rounding

Because tables present percentage figures rounded to the nearest whole number response percentages may not add up to 100%.

Statistical significance

Statistical tests were carried out on the data to determine whether there were any statistically significant differences between ages, where a question was asked across multiple questionnaires, and years, where a question was asked in 2016.

We used a 'z-test' to compare data for different age groups at the 95% confidence level.

A statistically significant difference means it is very unlikely that we would have obtained this result if there was no real difference.

Subgroup analysis

The multi-level analysis of subgroups highlights the experiences of different demographic sub-populations. Results for each demographic subgroup were generated as adjusted means (also known as estimated marginal means or population marginal means) using a linear mixed effects model. These means were compared within themes, derived from composites of questions, illustrated in the charts. This model takes into account trust clustering, as trusts are likely to have a big effect on reported patient experience at a national level.

To assess whether experience differs by demographic factors, statistical significance tests were carried out. F tests were performed on each factor (fixed effect) as a predictor of the target variable. P-values were also generated which showed how likely it is that the observed differences between groups could have arisen from a population where there were no actual differences. They relate to the demographic factor as a whole, rather than specific categories within the factor. Variables were also checked for multicollinearity.

Differences that are equivalent to at least 0.1 standard deviations from the overall mean of the target variable are treated as being noteworthy in this report, provided that the confidence interval does not overlap the mean line. The charts are in [appendix F](#), please note that the x-axis scale shows the average score-point difference associated with each demographic subgroup.

Design and interpretation of the questionnaire

An external advisory group ensured that a wide range of stakeholders had the opportunity to contribute to the development of this survey. Members included representatives from CQC, the Department of Health and Social Care, NHS England, NHS Youth Forum, specialist and non-specialist NHS acute trusts, and charities.

Questionnaires were extensively redeveloped for the 2016 survey. In contrast, only minor modifications were made to the questionnaires for the 2018 survey. To ensure historical comparability, across the three questionnaires, only two questions were removed and just three new questions were added. For full details, please see the [Survey Development Report](#).

Appendix A: Comparisons with other data

Currently there are no comparable national surveys of children and young people's hospital experiences to which we can compare the results of the 2018 Children and Young People's Patient Experience Survey. The [Royal College of Paediatrics and Child Health](#) has recommended that the existing inpatient survey conducted in Scotland should be extended to cover the views of children and young people.⁷⁷ The Bureau of Health Information in Australia conducts an [Admitted Children and Young Patients Survey](#) every three years, but the scope of this survey is more limited than CQC's children and young people's survey, as it is restricted to the experiences of only three specialist children's hospitals.⁷⁸

The [Child Hospital Survey](#) was designed to assess children's and their guardians' experiences of inpatient care in the US. While national results are published⁷⁹, to our knowledge, there is neither a systematic reporting schedule nor a restricted sampling period. These considerations and others complicate comparisons with this survey.

Comparison with the 2018 Adult inpatient survey

Differences in patient populations sampled (for example, the adult inpatient survey does not include day case patients, and the children's survey has a combination of feedback from patients and their parents and carers), sampling period, question wording and response options mean that the results of the [2018 Adult inpatient survey](#) are not directly comparable with the results of the 2018 children and young people's patient experience survey. Although the surveys cover different patient groups and have other methodological differences, in this section we explore similarities and differences in patient experience across the surveys.

Admission

Both surveys featured a question on whether admission dates for elective patients had been changed prior to the hospital stay. Findings were quite consistent: in this survey, 83% of parents of children aged 0 to 7 said that their child's admission date had not been changed and, in the 2018 adult inpatient survey, 80% said that their admission date had not been changed.

Cleanliness

Both surveys featured a question on the cleanliness of the hospital ward or room. In the 2018 adult inpatient survey 69% of respondents said the ward or room was 'very clean'. Results are similar for this survey, where two thirds of parents of children aged 0 to 15 (67%) said the room or ward their child has stayed in was 'very clean'.

Privacy

In the 2018 adult inpatient survey, 90% said they were 'always' given enough privacy when they were examined or treated. Figures were less positive in this survey: 82%

of children and young people aged 8 to 15 and 84% of parents of children aged 0 to 7 said they/their child were 'always' given enough privacy when they received care and treatment.

Confidence and trust in staff

In the 2018 adult inpatient survey, 79% said they 'always' had confidence and trust in doctors and 77% said they 'always' had confidence and trust in nurses. A similar percentage (80%) of parents and carers of children and young people aged 0 to 15 said they 'always' had confidence and trust in the staff who had treated their child.

Involvement

Both surveys featured a question on patient involvement in decisions about care and treatment. In the adult inpatient survey, patients were asked 'Were you involved as much as you wanted to be in decisions about your care and treatment?'. In this survey, children and young people aged 8 to 15 were asked 'Were you involved in decisions about your care and treatment?'. Results were less positive in this survey: 54% of adult inpatients said 'yes, definitely', but 46% of children and young people said 'yes, a lot'.

Pain management

In the 2018 adult inpatient survey, 67% said the hospital staff 'definitely' did everything they could to control their pain. Responses were more positive in this survey: 79% of children aged 8 to 15 who felt pain said that staff had done everything they could to help them and 73% of parents of children aged 0 to 15 said that staff 'definitely' did everything they could to help their pain.

Operations and procedures

Both surveys asked patients about communication before and after operations and procedures. Responses were more positive in this survey. First, while in the 2018 adult inpatient survey, 80% said that staff had 'completely' answered their questions before the operation or procedure in a way they could understand, in this survey 90% of parents of children aged 0 to 15 said that staff had 'completely' answered their questions in a way they could understand.

Second, similarly, while in the 2018 adult inpatient survey 67% of patients said that staff had 'completely' explained how the operation or procedure had gone in a way they could understand, in this survey 79% of children and young people aged 8 to 15 said that staff had explained how the operations or procedures had gone (but note that adult inpatient survey question may be a 'tougher test' because the children's question did not include the phrase 'in a way you could understand').

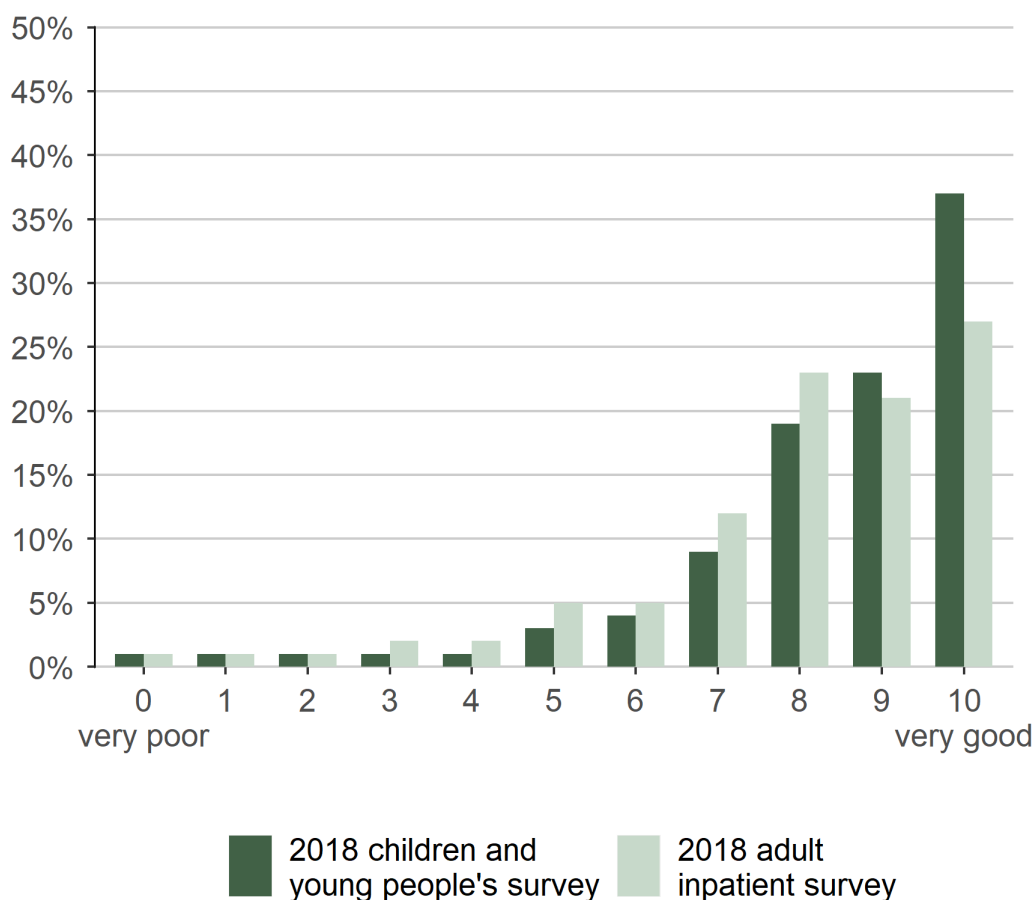
Leaving hospital

Both surveys featured the question "When you left hospital, did you know what would happen next with your care?". Figures were more positive for this survey. Just over one in ten children and young people aged 8 to 15 (11%) and fewer than one in ten (7%) parents of children aged 0 to 15 said 'no'. In contrast, nearly one in five patients said 'no' in the 2018 adult inpatient survey (18%).

Overall experience

Both surveys featured a question on overall experiences of care, which asked respondents to rate their or their child's care on a scale from 0 (I had/I felt that my child had a very poor experience) to 10 (I had/felt that my child had a very good experience). Responses were more positive for this survey. While in the 2018 adult inpatient survey less than half (48%) of patients selected a score of 9 or 10, in this survey 61% of parents of children and young people aged 0 to 15 selected a score of 9 or 10.

Response percentages for Likert-type overall evaluation of care questions (overall... I had/felt that my child had a very good experience) for the 2018 Children and young people's survey and 2018 Adult inpatient survey.



Note: Number of respondents: 2018 children and young people's survey (32,184), 2018 adult inpatient survey (72,319).

Appendix B: Main users of the survey data

This appendix lists known users of data from the Children and young people's survey and how they use the data. We have been reviewing the use of all survey data to identify who uses it. We would like to hear from anyone interested in, or already using, data to contact us with feedback or recommendations at: patient.survey@cqc.org.uk.

NHS trusts and commissioners

Trusts, and those who commission services, use the results to help identify and make the improvements they need to improve the experience of people who use their services.

Patients, their supporters and representative groups

CQC publishes the survey results for each participating NHS trust. This appears on the trust's profile page on our website (www.cqc.org.uk). You can find this by searching for the name of the organisation using the search function. The data is presented in an accessible format alongside inspection results to enable the public to examine how services are performing.

Care Quality Commission (CQC)

CQC uses the results from the survey in the regulation, monitoring and inspection of NHS acute trusts in England. Survey data is used in our CQC Insight monitoring tool, which provides inspectors with an assessment of how trusts are performing. The survey data will also be included in the evidence appendices to inform our inspections and as a key source of evidence to support the judgements and ratings for trusts.

NHS England and NHS Improvement

NHS England and NHS Improvement will use the data to inform how it addresses the challenges currently facing the NHS across the country. To help drive improvement and to inform its oversight work, it will also conduct further analysis of the data, making comparisons (where possible) with the experiences of children and young people in other care settings.

Appendix C: Quality and methodology

Quality and methodology document

All detail on data limitations can be found in the quality and methodology document, available at: www.cqc.org.uk/childrensurvey

Revisions and corrections

CQC publishes a [Revisions and Corrections Policy](#) relating to these statistics.

NHS Patient Survey Programme data is not subject to any scheduled revision as they capture the views of patients about their experiences of care at a specific point in time. All new survey results are therefore published on CQC's website and NHS Surveys, as appropriate, and previously published results for the same survey are not revised.

This policy sets out how CQC will respond if an error is identified within published data and if it becomes necessary to correct data and/or reports.

Appendix D: Other sources of information related to survey results

Standards for children and young people's healthcare

Key standards for children and young people's NHS care are [National Service Framework for Children, Young People and Maternity Services](#), [Getting the right start: National Service Framework for Children - Standard for Hospital Services](#), and [You're Welcome - Quality criteria for young people friendly health services](#). The World Health Organization's [Standards for improving the quality of care for children and young adolescents in health facilities](#) offers an international perspective.

NICE guidance

A counterpart to [Patient experience in adult NHS services: improving the experience of care for people using adult NHS services](#), specifically tailored to the experiences of children and young people is [in development](#). A NICE guideline on transition, [Transition from children's to adults' services for young people using health or social care services](#), is available.

NHS Patient Experience Framework

In October 2011, the NHS National Quality Board (NQB) agreed on a working definition of patient experience to guide the measurement of patient experience across the NHS. The NHS Patient Experience Framework outlines those elements that are of critical importance to patients' experiences of NHS Services. For further information on the NHS patient experience framework, please see: www.gov.uk/government/publications/nhs-patient-experience-framework

Staffing

For further information on counts of staff please see NHS Digital's statistical release on NHS Workforce Statistics. Please note this data includes acute, community and mental health trusts:

<https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics>

Children and young people's accident and emergency activity

NHS digital's annual publication on [hospital accident and emergency activity](#) contains accident emergency activity data for five groups of children and young people: children aged 0, 1 to 4, 5 to 9, 10 to 14, and 15.

Appendix E: Further information and feedback

Further information

The 'technical document' describes the methodology for analysing the trust level results and a 'quality and methodology' document provides information about the survey development and methodology: www.cqc.org.uk/childrensurvey

Full details of the methodology for the survey, including questionnaires, letters sent to people who use services, instructions on how to carry out the survey and the survey development report, are available at:

<https://nhssurveys.org/surveys/survey/01-children-patient-experience/year/2018/>

More information on the patient survey programme, including results from other surveys and a programme of current and forthcoming surveys can be found at: www.cqc.org.uk/surveys

Further questions

This summary has been produced by CQC's Surveys Team and reflects the findings of the 2018 Children and young people's patient experience survey. The guidance above should help answer any questions about the programme. If you wish to contact the Team directly, please contact Tamatha Webster, Survey Manager, Patient.Survey@cqc.org.uk.

Feedback

We welcome all feedback on the findings of the survey and the way we have reported the results – particularly from people using services, their representatives, and those providing services. If you have any views, comments or suggestions on how we could improve this publication, please contact Tamatha Webster, Survey Manager, Patient.Survey@cqc.org.uk.

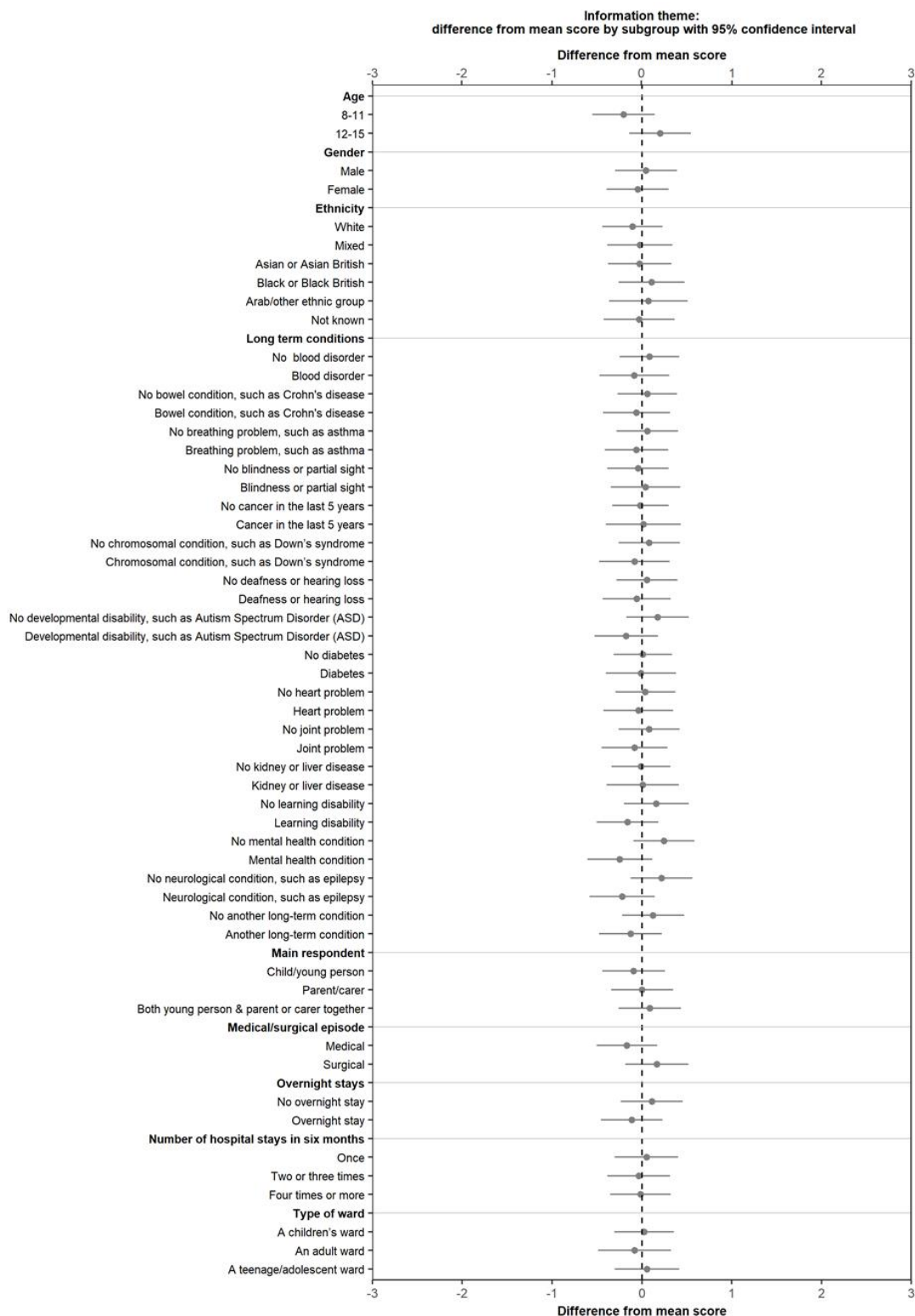
We will review your feedback and use it as appropriate to improve the statistics that we publish across the NHS Patient Survey Programme.

If you would like to be involved in consultations or receive updates on the NHS Patient Survey Programme, please subscribe [here](#).

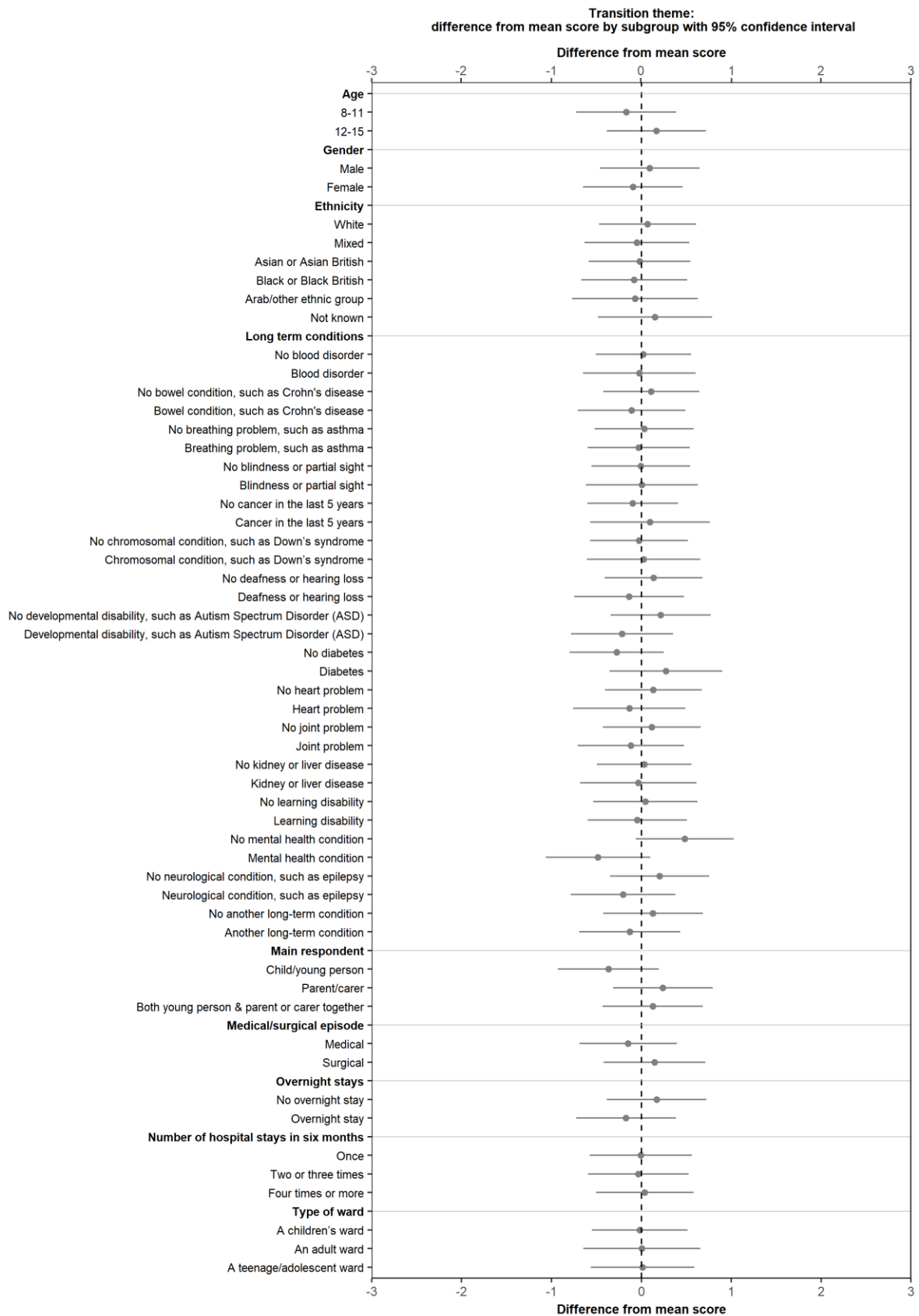
Appendix F: Subgroup analysis charts

Children and young people aged 8 to 15

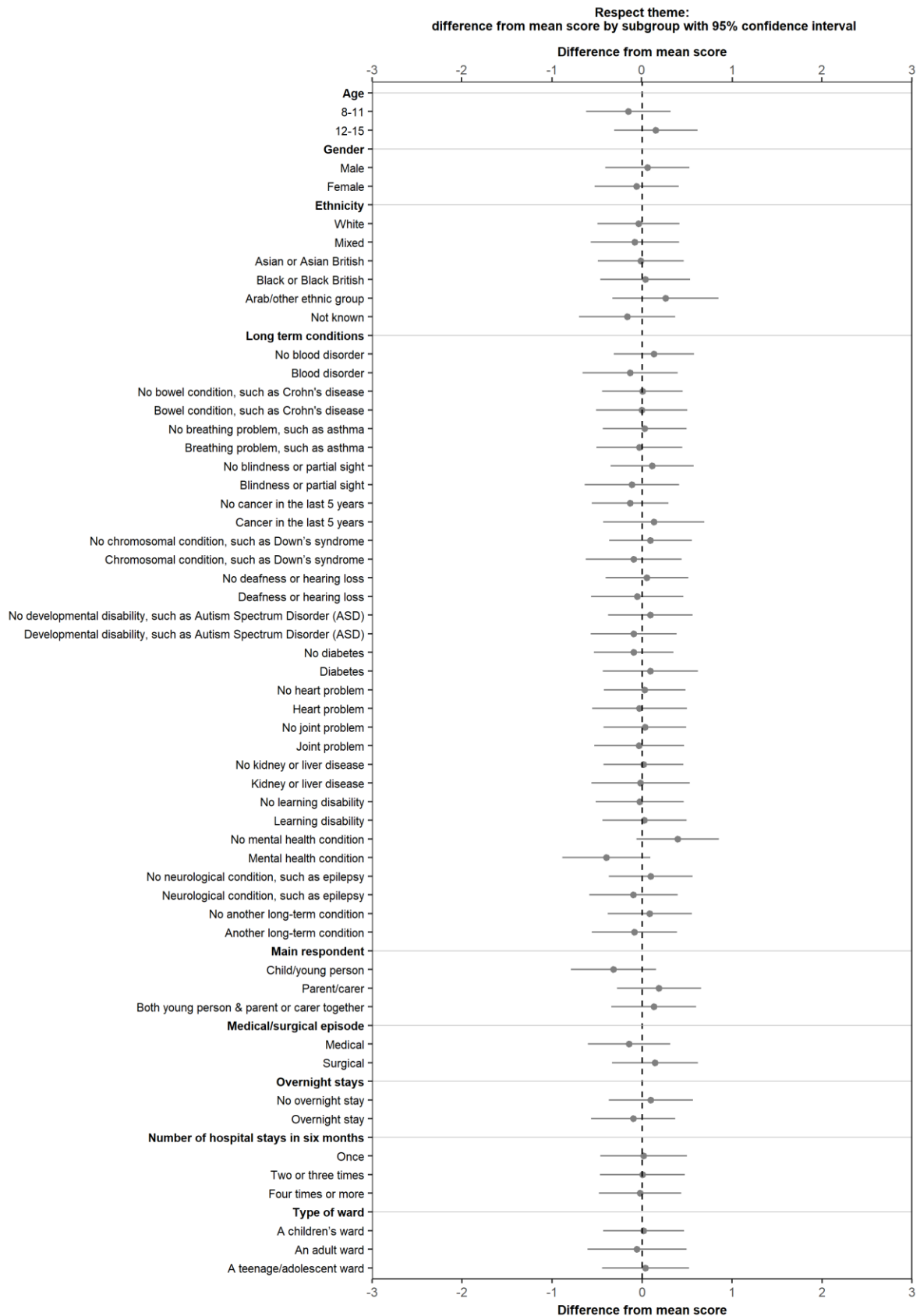
Information and communication



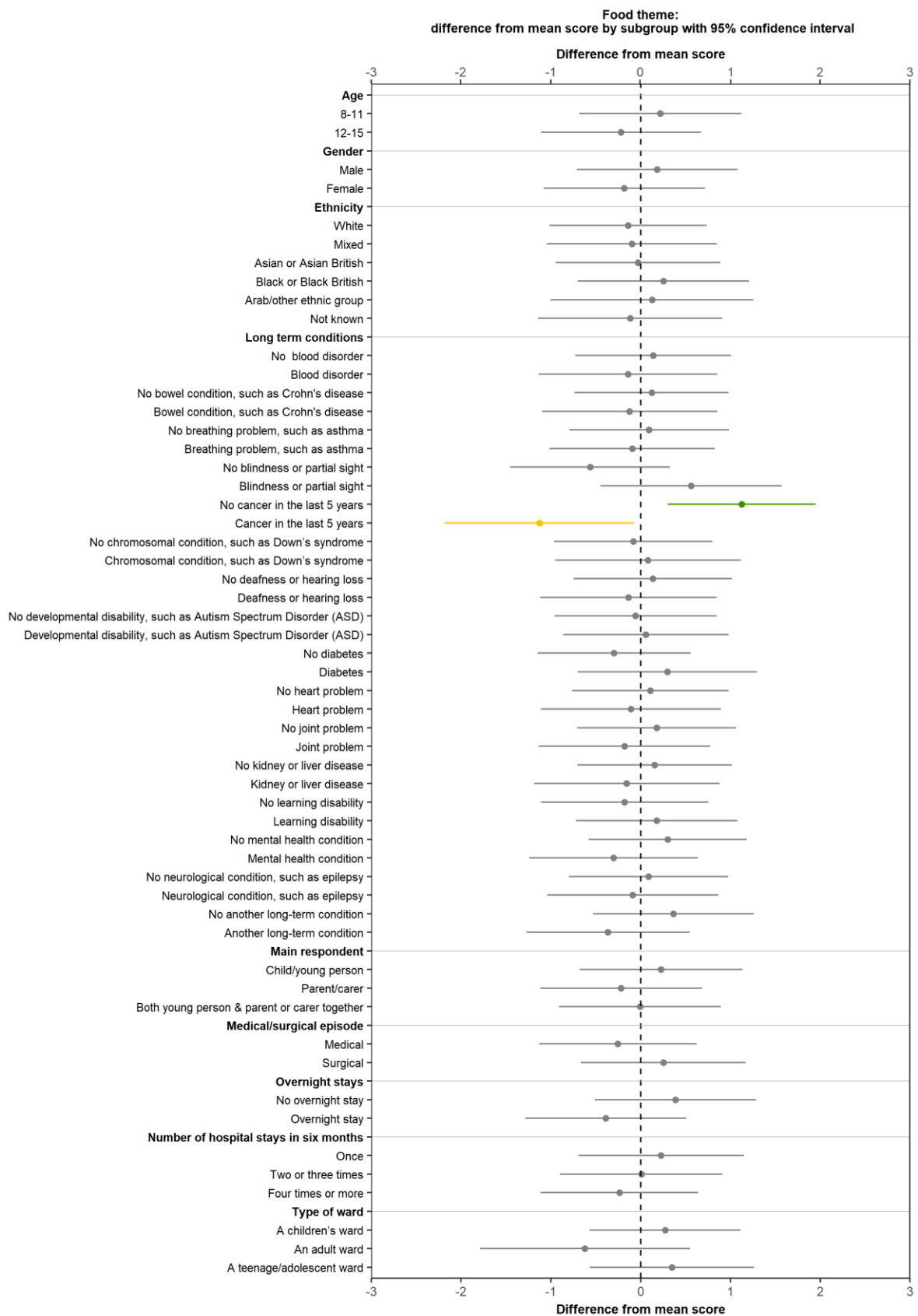
Transition and continuity



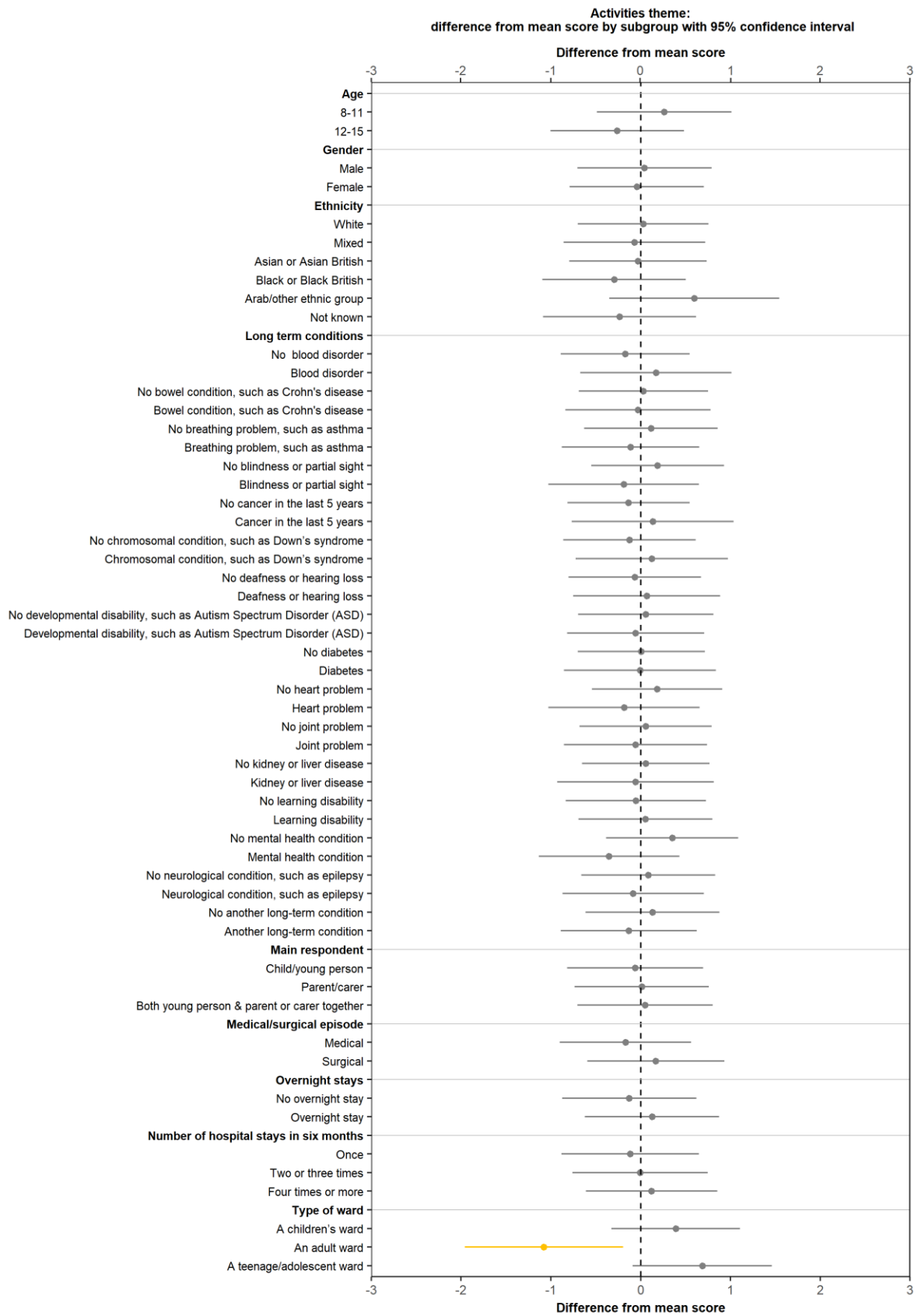
Respect for patient centred values, preferences and expressed needs



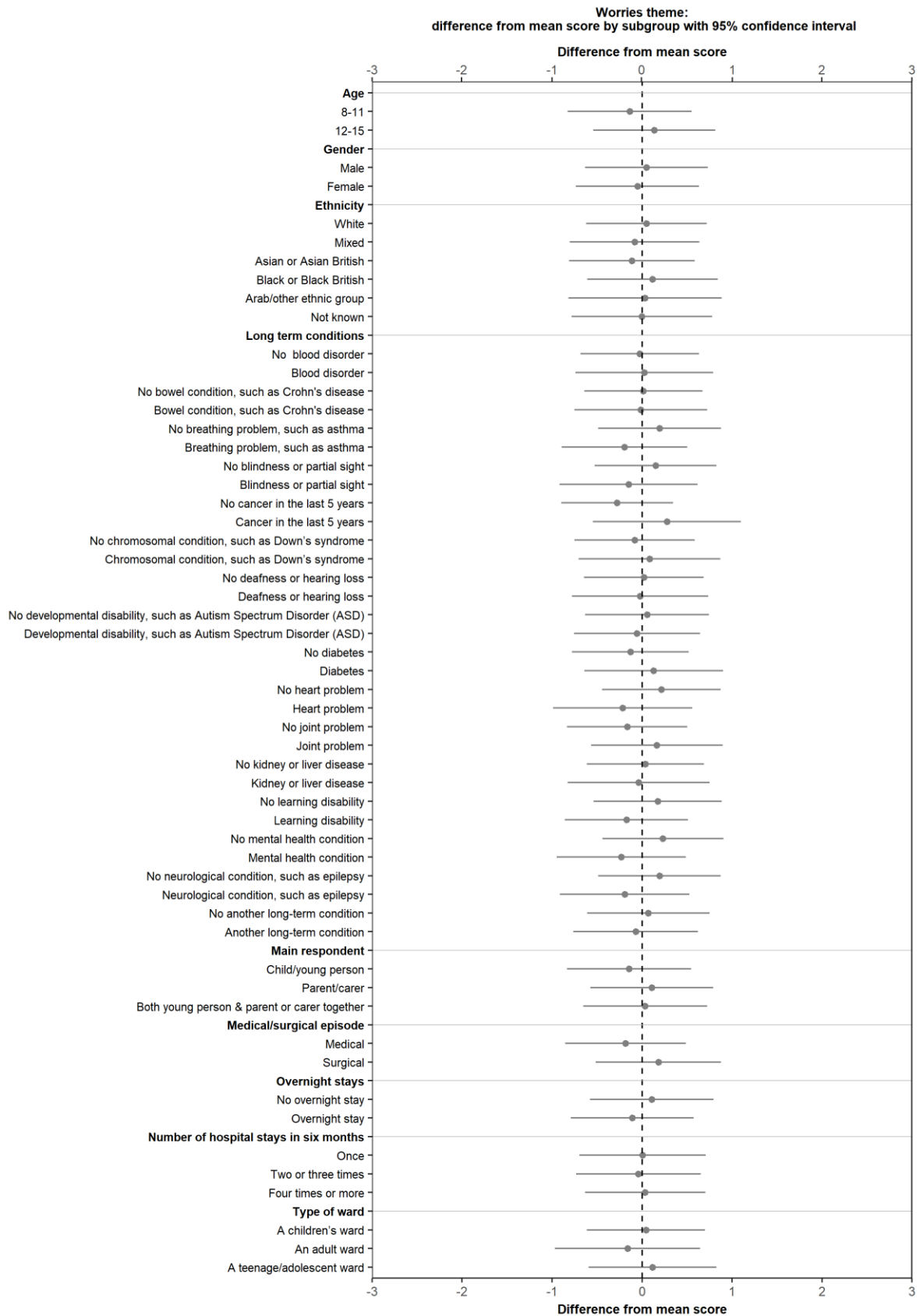
Food



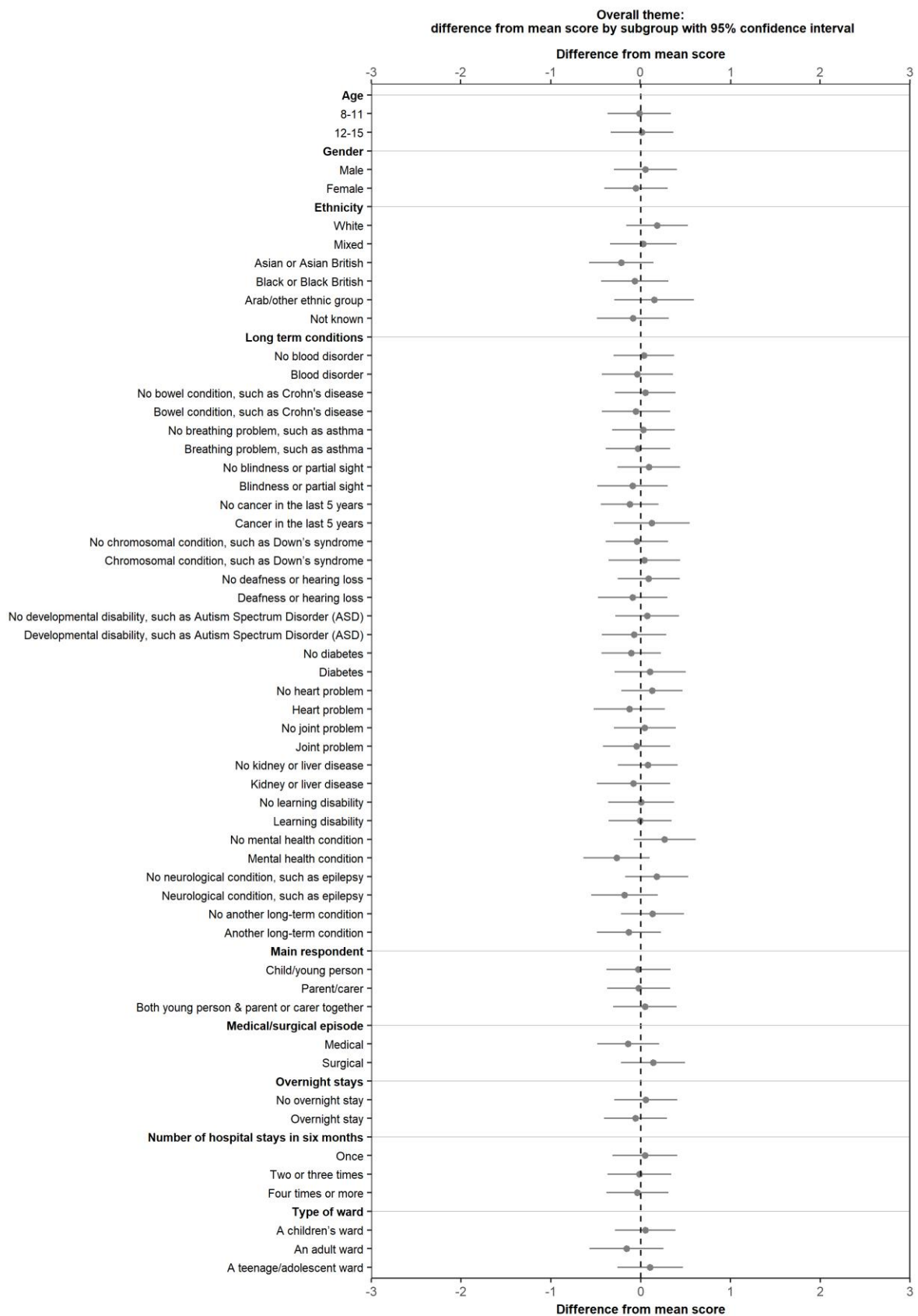
Enough things to do



Emotional support

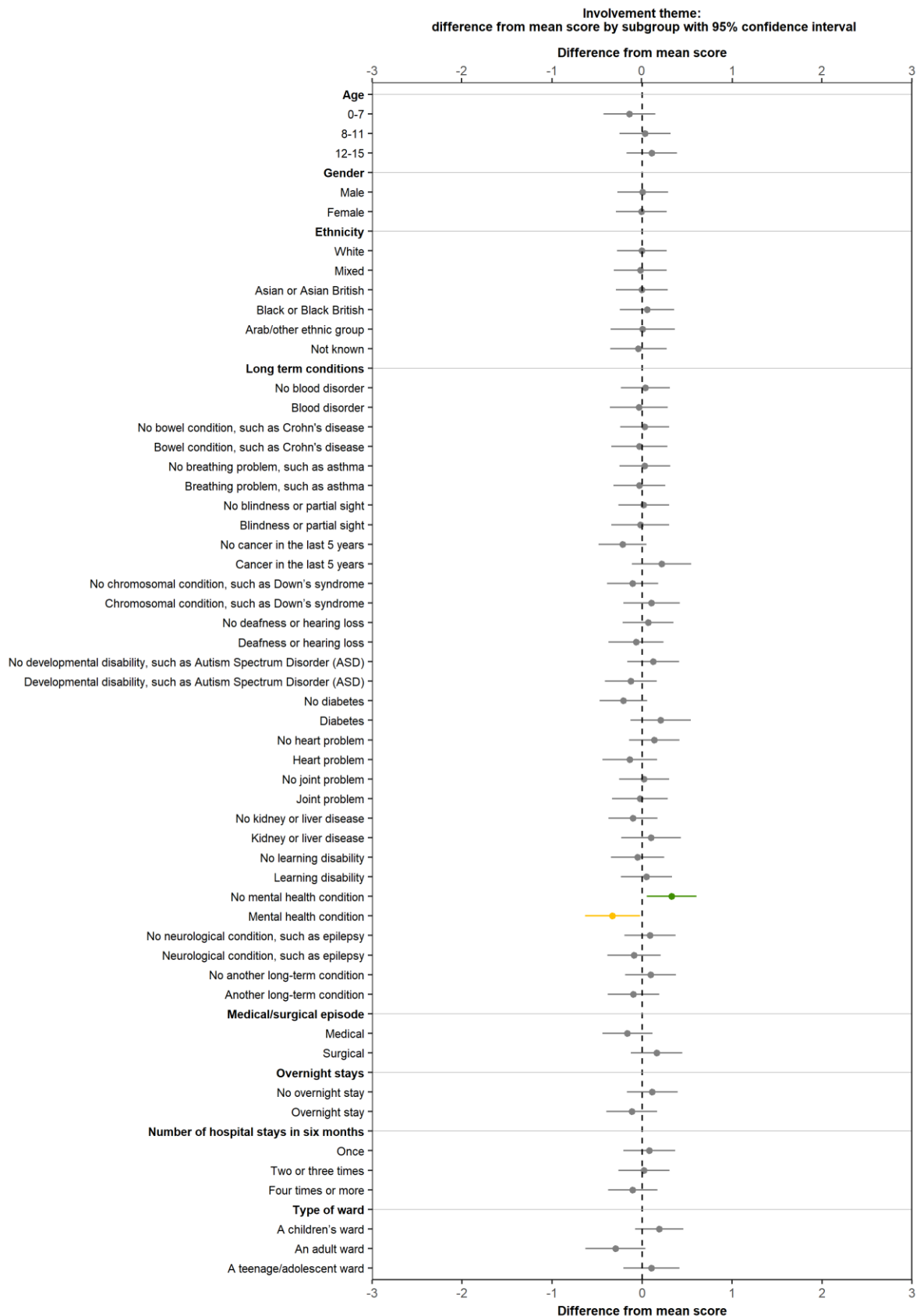


Children feeling well looked after

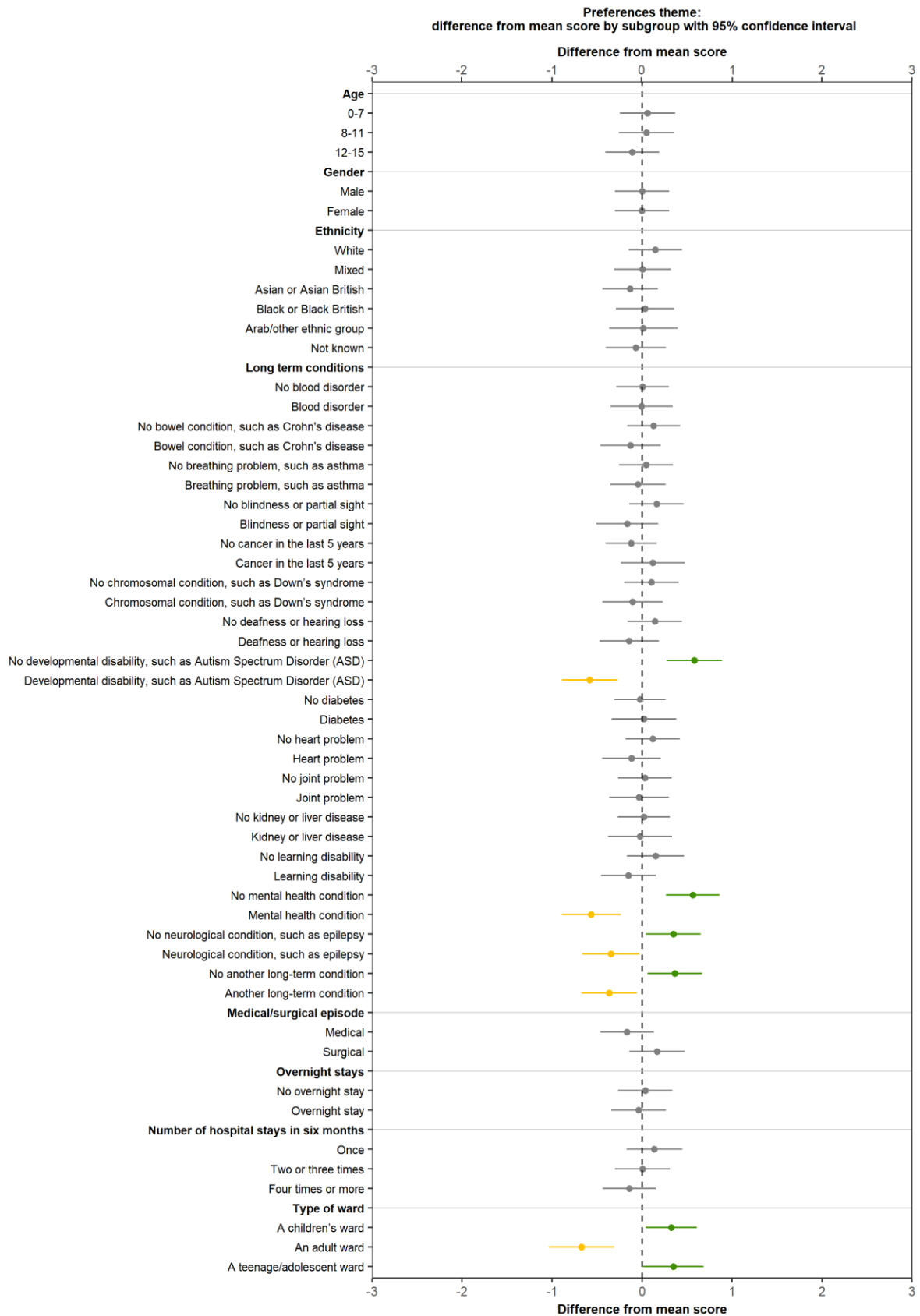


Parents and carers 0 to 15

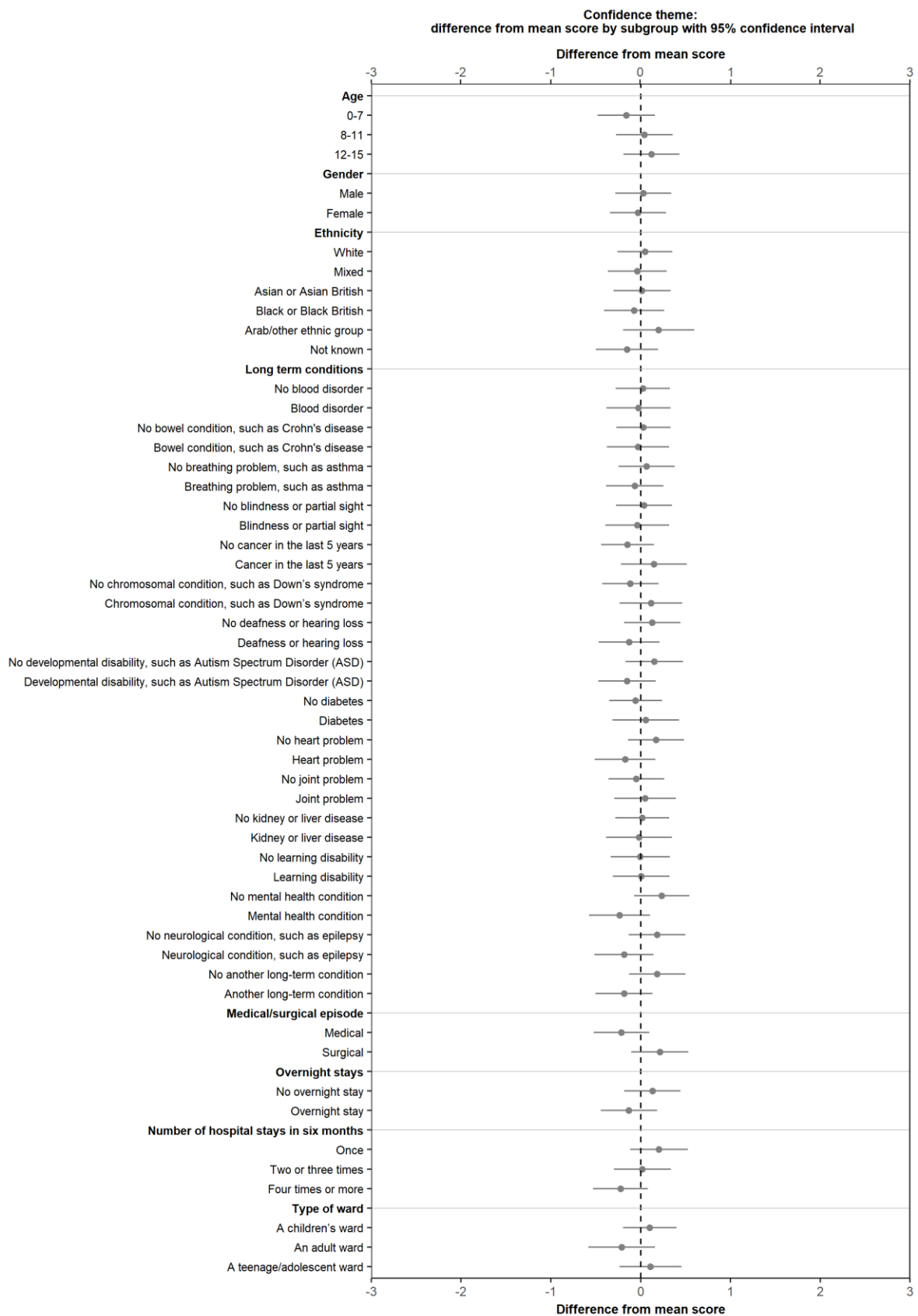
Welcoming the involvement of family and friends



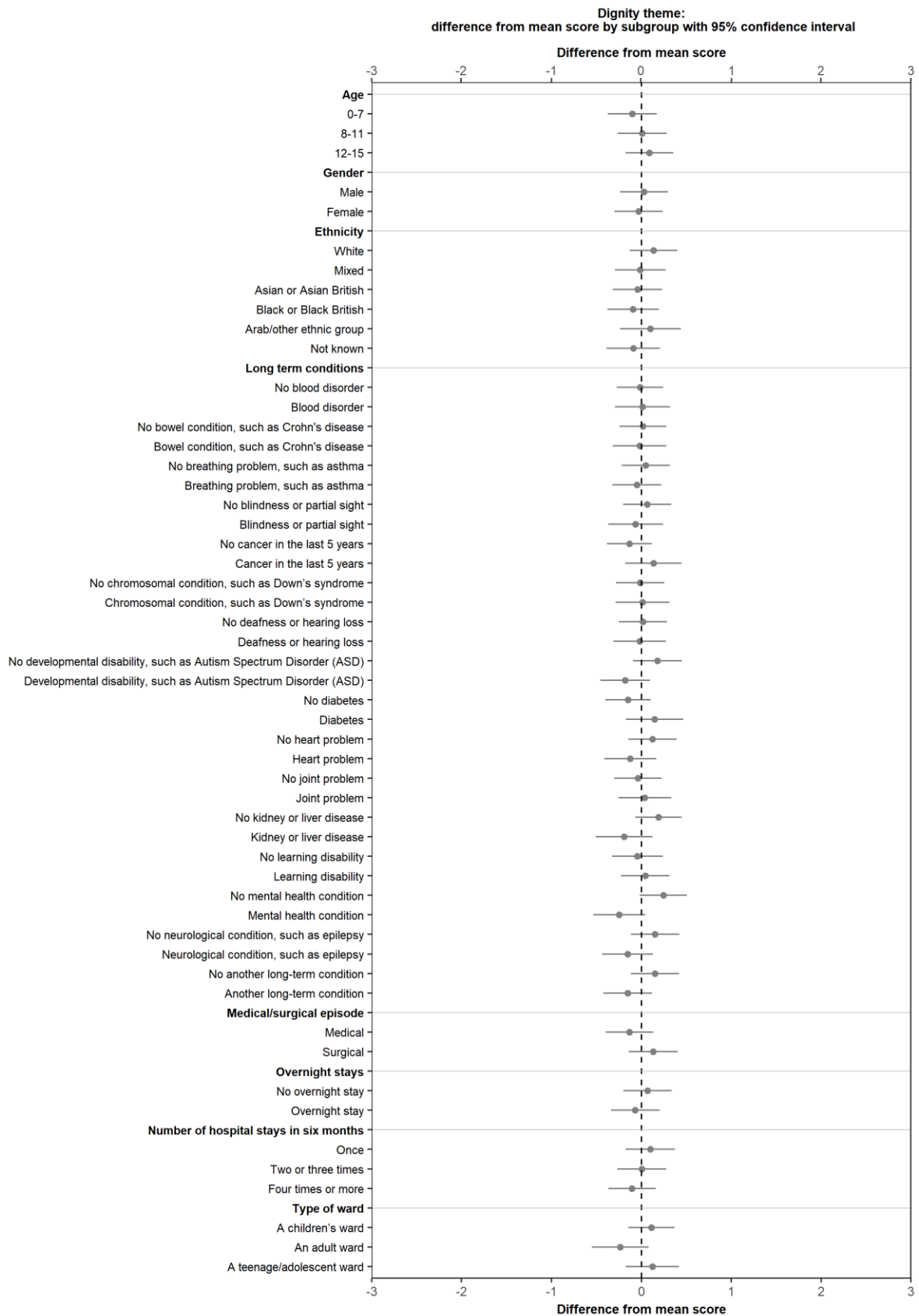
Respect for the child's individual needs and preferences



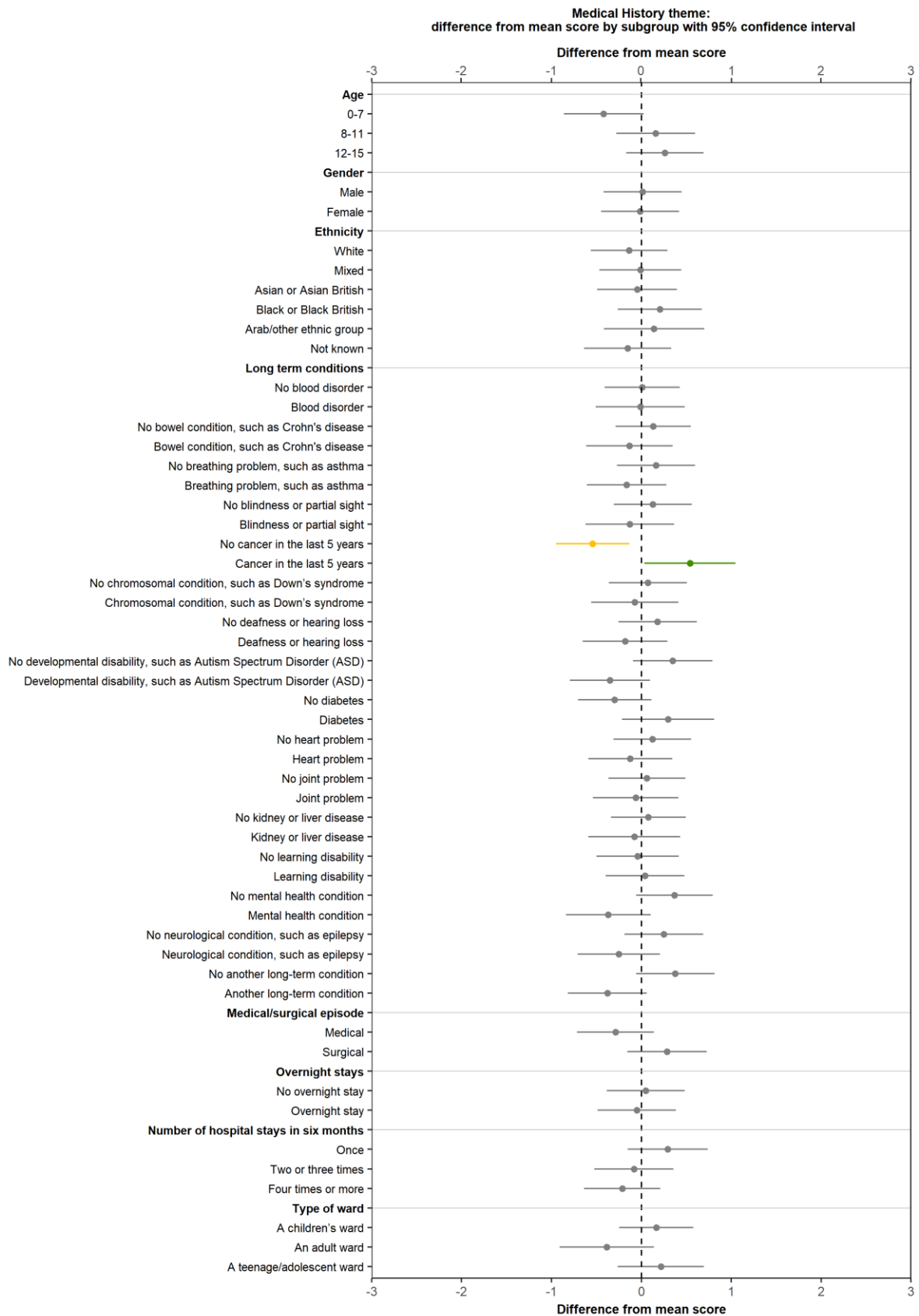
Confidence and trust



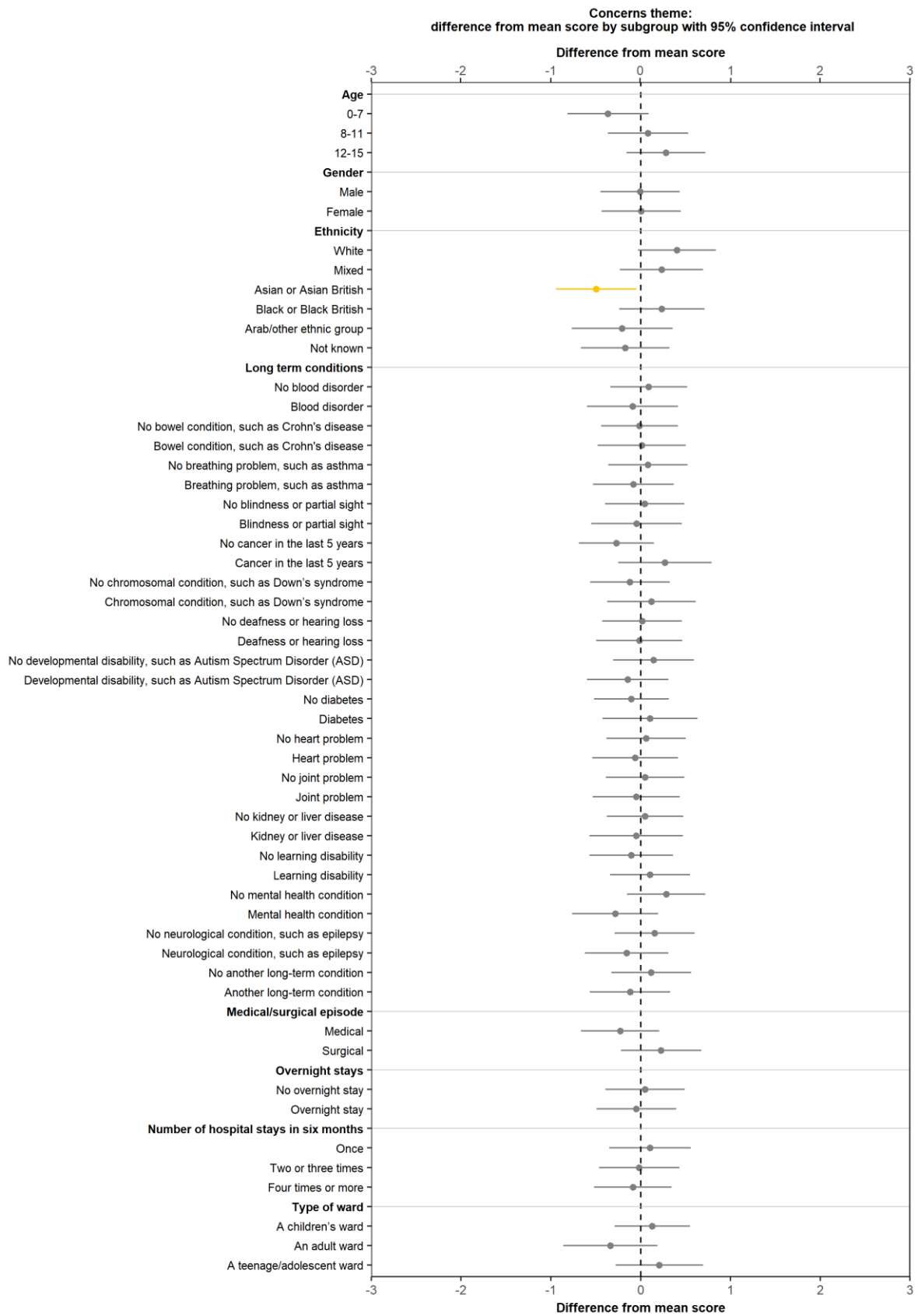
Dignity and respect



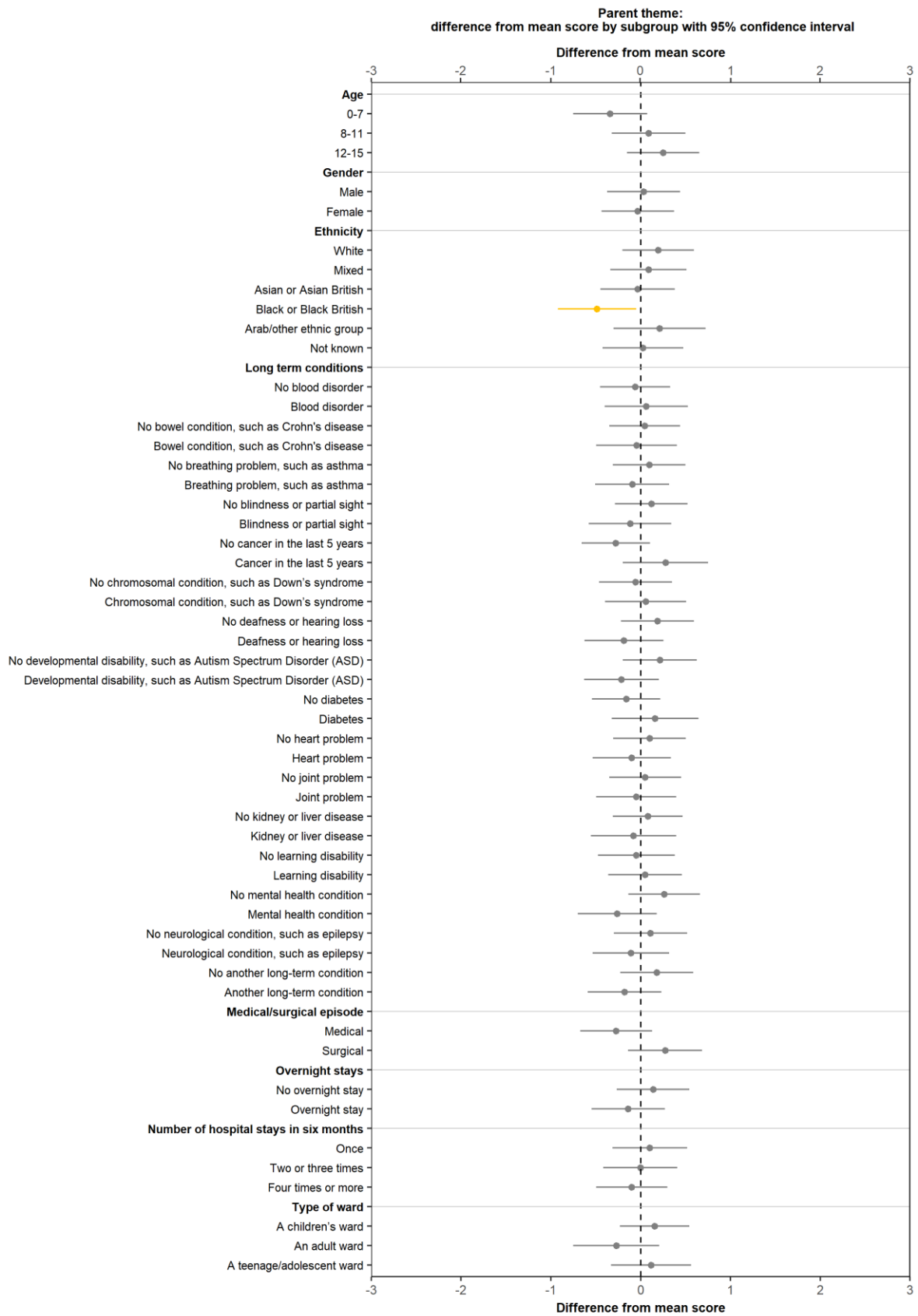
Awareness of medical history



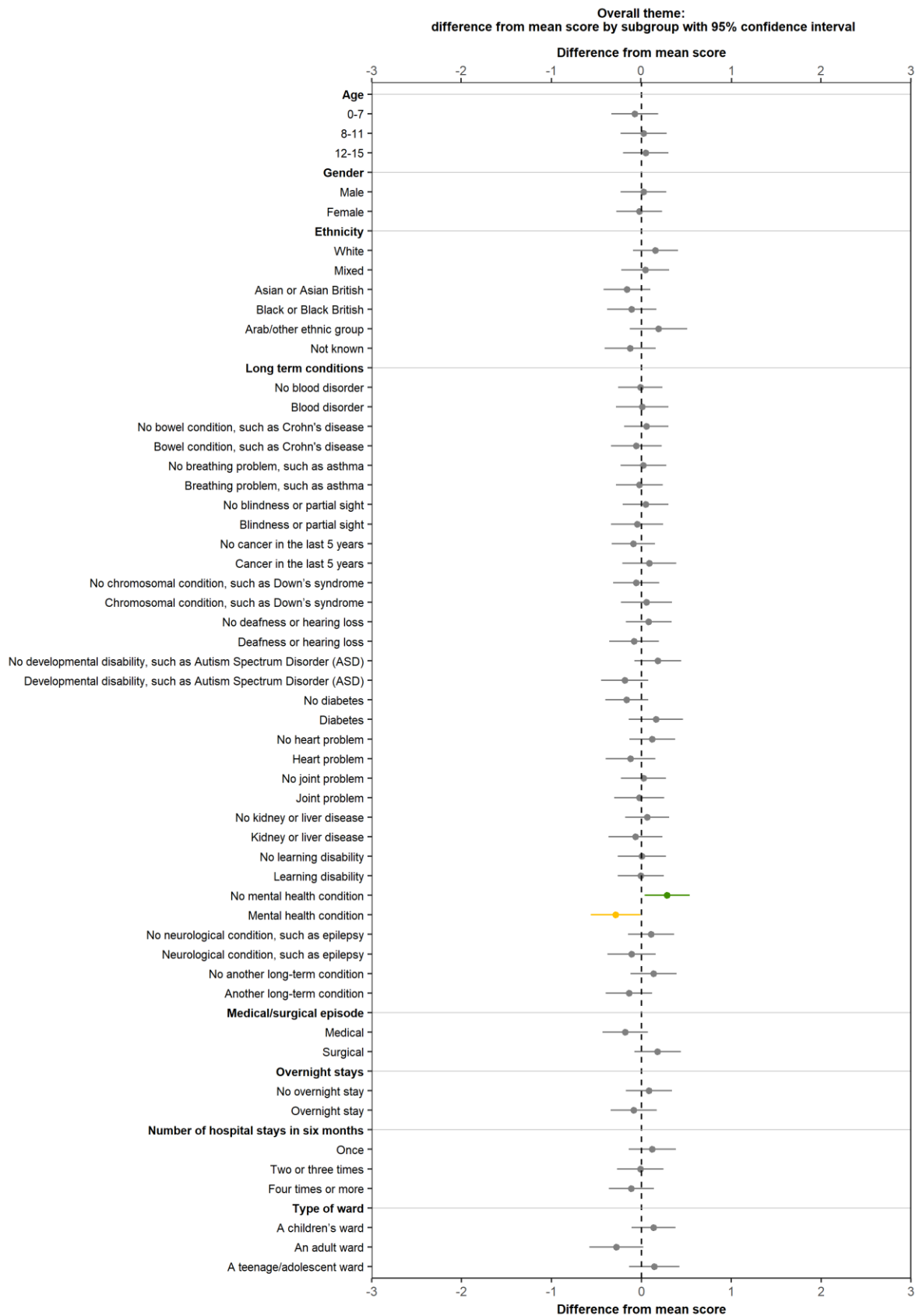
Feeling able to raise concerns



Parents feeling well looked after



Children's overall experience



Appendix G: Question mapping

The table below identifies each survey question's national result question ID and question number in each of the three questionnaires, where applicable.

Questionnaire				
ID	0-7	8-11	12-15	Question text
X3	Q3	N/A	N/A	Did the hospital give you a choice of admission dates?
X4	Q4	N/A	N/A	Did the hospital change your child's admission date at all?
X5	Q5	Q26	Q27	For most of their stay in hospital, what type of ward did your child stay on?
X6	Q6	Q27	Q28	Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?
X7	Q7	Q28	Q29	How clean do you think the hospital room or ward was that your child was in?
X8	Q8	N/A	N/A	Was your child given enough privacy when receiving care and treatment?
X9	Q9	N/A	N/A	Were there enough things for your child to do in the hospital?
X10	Q10	N/A	N/A	Did staff play with your child at all while they were in hospital?
X11	Q11	N/A	N/A	If your child used the hospital Wi-Fi to entertain themselves, was it good enough to do what they wanted?
X12	Q12	N/A	N/A	Did new members of staff treating your child introduce themselves?
X13	Q13	Q29	Q30	Did members of staff treating your child give you information about their care and treatment in a way that you could understand?
X14	Q14	N/A	N/A	Did members of staff treating your child communicate with them in a way that your child could understand?
X15	Q15	Q30	Q31	Did a member of staff agree a plan for your child's care with you?

X16	Q16	Q31	Q32	Did you have confidence and trust in the members of staff treating your child?
X17	Q17	Q32	Q33	Did staff involve you in decisions about your child's care and treatment?
X18	Q18	Q33	Q34	Were you given enough information to be involved in decisions about your child's care and treatment?
X19	Q19	Q34	Q35	Did hospital staff keep you informed about what was happening whilst your child was in hospital?
X20	Q20	Q35	Q36	Were you able to ask staff any questions you had about your child's care?
X21	Q21	N/A	N/A	Did different staff give you conflicting information?
X22	Q22	Q36	Q37	Were the different members of staff caring for and treating your child aware of their medical history?
X23	Q23	Q37	Q38	Did you feel that staff looking after your child knew how to care for their individual or special needs?
X24	Q24	Q38	Q39	Were members of staff available when your child needed attention?
X25	Q25	Q39	Q40	Did the members of staff caring for your child work well together?
X26	Q26	Q40	Q41	If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?
X27	Q27	N/A	N/A	Did your child like the hospital food provided?
X28	Q28	Q41	Q42	Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)
X29	Q29	Q42	Q43	Were you able to prepare food in the hospital if you wanted to?
X31	Q31	Q44	Q45	How would you rate the facilities for parents or carers staying overnight?
X32	Q32	Q45	Q46	If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?

X34	Q34	Q47	Q48	Before your child had any operations or procedures did a member of staff explain to you what would be done?
X35	Q35	Q48	Q49	Before the operations or procedures, did a member of staff answer your questions in a way you could understand?
X36	Q36	Q49	Q50	During any operations or procedures, did staff play with your child or do anything to distract them?
X37	Q37	Q50	Q51	Afterwards, did staff explain to you how the operations or procedures had gone?
X38	Q38	Q51	Q52	Did a staff member give you advice about caring for your child after you went home?
X39	Q39	N/A	N/A	Did a member of staff tell you who to talk to if you were worried about your child when you got home?
X40	Q40	Q52	Q53	When you left hospital, did you know what was going to happen next with your child's care?
X41	Q41	Q53	Q54	Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?
X42	Q42	N/A	N/A	Do you feel that the people looking after your child listened to you?
X43	Q43	N/A	N/A	Do you feel that the people looking after your child were friendly?
X44	Q44	N/A	N/A	Do you feel that your child was well looked after by the hospital staff?
X45	Q45	Q54	Q55	Do you feel that you (the parent/carer) were well looked after by hospital staff?
X46	Q46	Q55	Q56	Were you treated with dignity and respect by the people looking after your child?
X47	Q47	Q56	Q57	Overall... I felt that my child had a very poor experience (0) to I felt that my child had a very good experience (10) (please circle a number)
X48	N/A	Q1	N/A	Did hospital staff play with you or do any activities with you while you were in hospital?
X49	N/A	N/A	Q1	Was the ward suitable for someone of your age?

X50	N/A	Q2	Q2	Were there enough things for you to do in the hospital?
X51	N/A	Q3	Q3	If you used the hospital Wi-Fi, was it good enough to do what you wanted?
X52	N/A	Q4	Q4	Did you like the hospital food?
X53	N/A	Q5	Q5	Was it quiet enough for you to sleep when needed in the hospital?
X54	N/A	Q6	Q6	Did hospital staff talk with you about how they were going to care for you?
X55	N/A	Q7	Q7	When the hospital staff spoke with you, did you understand what they said?
X56	N/A	Q8	Q8	Did you feel able to ask staff questions?
X57	N/A	Q9	Q9	Did the hospital staff answer your questions?
X58	N/A	Q10	Q10	Were you involved in decisions about your care and treatment?
X59	N/A	Q11	Q11	If you had any worries, did a member of staff talk with you about them?
X60	N/A	Q12	Q12	Were you given enough privacy when you were receiving care and treatment?
X61	N/A	N/A	Q13	If you wanted, were you able to talk to a doctor or nurse without your parent or carer being there?
X62	N/A	Q13	Q14	If you felt pain while you were at the hospital, do you think staff did everything they could to help you?
X64	N/A	Q15	Q16	Before the operations or procedures, did hospital staff explain to you what would be done?
X65	N/A	Q16	Q17	Afterwards, did staff explain to you how the operations or procedures had gone?
X66	N/A	Q17	Q18	Did a member of staff tell you who to talk to if you were worried about anything when you got home?
X67	N/A	Q18	Q19	When you left hospital, did you know what was going to happen next with your care?

X68	N/A	Q19	Q20	Did a member of staff give you advice on how to look after yourself after you went home?
X69	N/A	Q20	Q21	Do you feel that the people looking after you were friendly?
X70	N/A	Q21	Q22	Overall, how well do you think you were looked after in hospital?

Appendix H: Acknowledgements

CQC would like to thank the stakeholders who helped us to redevelop the children and young people's questionnaires and supporting materials. We particularly appreciate the guidance and support given by the Survey Advisory Group, which this year included representatives from NHS England and NHS Improvement, NHS Youth Forum, the Department of Health and Social Care, Great Ormond Street Hospital for Children NHS Foundation Trust, Northern Devon Healthcare NHS Trust, Royal Brompton and Harefield NHS Foundation Trust and CLIC Sargent.

We are grateful to all the thousands of children, young people, parents and carers who took the time to provide feedback on their experiences of care in hospital.

We would also like to thank the teams involved in sampling at each NHS trust, without which national surveys of care experience would not be possible.

This survey used, under licence, questionnaires originally developed and owned by Picker Institute Europe.

References

- ¹ Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*, 3:e001570. doi: 10.1136/bmjopen-2012-001570
- ² Department of Health and Social Care, *NHS Patient Experience Framework*, February 2012. <https://www.gov.uk/government/publications/nhs-patient-experience-framework>
- ³ NHS Improvement, *Patient experience improvement framework*, June 2018. https://improvement.nhs.uk/documents/2885/Patient_experience_improvement_framework_full_publication.pdf
- ⁴ National Institute for Health and Care Excellence, *Patient experience in adult services: improving the experience of care for people using adult NHS services*, February 2012. <https://www.nice.org.uk/guidance/cg138>
- ⁵ NHS Digital website (accessed October 2019). <https://digital.nhs.uk/data-and-information/publications/ci-hub/nhs-outcomes-framework>
- ⁶ Department of Health and Social Care, *The NHS Constitution for England*, October 2015. <https://www.gov.uk/government/publications/the-nhs-constitution-for-england>
- ⁷ Department of Health and Social Care, *NHS mandate 2018 to 2019*, March 2018. <https://www.gov.uk/government/publications/nhs-mandate-2018-to-2019>
- ⁸ NHS England, *The NHS Long Term Plan*, January 2019. <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>
- ⁹ NHS England, *Shared commitment to quality from the National Quality Board*, December 2016. <https://www.england.nhs.uk/wp-content/uploads/2016/12/nqb-shared-commitment-frmrwrk.pdf>
- ¹⁰ Hargreaves, D. S., & Viner, R. M. (2012). Children's and young people's experience of the National Health Service in England: A review of national surveys. *Archives of Disease in Childhood*, 97, 661-666. <http://dx.doi.org/10.1136/archdischild-2011-300603>
- ¹¹ Hargreaves, D. S. et al. (2018). Measuring and improving the quality of NHS care for children and young people. *Archives of Diseases in Childhood*, 103, 316-318. <https://adc.bmj.com/content/104/7/618.abstract>
- ¹² National Institute for Health and Care Excellence, *Guideline scope: Babies, children and young people's experience of healthcare*. April, 2019. <https://www.nice.org.uk/guidance/gid-ng10119/documents/final-scope>
- ¹³ Hargreaves, D. S., Sizmur, S., Pitchforth, J., Tallet, A., Toomey, S. J., Hopwood, B., Schuster, M. A., & Viner, R. M. (2018). Children and young people's versus parents' response in an English national inpatient survey. *Archives of Disease in Childhood*, 103, 486-491. <http://dx.doi.org/10.1136/archdischild-2017-31380>

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- ¹⁴ Department of Health, *National Service Framework for Children, Young People and Maternity Services*, 2004. <https://www.gov.uk/government/publications/national-service-framework-children-young-people-and-maternity-services>
- ¹⁵ Department of Health, *Getting the right start: National Service Framework for Children – Standard for Hospital Services*, April 2003. https://www.nhs.uk/nhsengland/aboutnhservices/documents/nsf%20children%20in%20hospitalldh_4067251%5b1%5d.pdf
- ¹⁶ Department of Health, *You're Welcome – Quality criteria for young people friendly health services*. April, 2011. <https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services>
- ¹⁷ Care Quality Commission, *The state of health care and adult social care in England 2018/19*. October, 2019. https://www.cqc.org.uk/sites/default/files/20191015b_stateofcare1819_fullreport.pdf
- ¹⁸ Care Quality Commission, *The state of care in NHS acute hospitals 2014 to 2016*. 2017. http://www.cqc.org.uk/sites/default/files/20170302b_stateofhospitals_web.pdf
- ¹⁹ National Institute for Health and Care Excellence, *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services*. February, 2012. <https://www.nice.org.uk/guidance/cg138/chapter/Introduction>
- ²⁰ Weil, G. L., Lemer, C., Webb, E., & Hargreaves, D. S. (2015). The voices of children and young people in health: where are we now? *Archives of Disease in Childhood*, 100, 915-917. <https://adc.bmj.com/content/100/10/915>
- ²¹ Whiting, L., Roberts, S., Petty, J., Meager, G., & Evans, K. (2018). Work of the NHS England Youth Forum and its effect on health services. *Nursing Children and Young People*. doi:10.7748/ncyp.2018.e1074
- ²² NHS Youth Forum, *Youth Rights in Healthcare*. <https://www.england.nhs.uk/wp-content/uploads/2015/08/youth-rights-in-hlthcr-er.pdf>
- ²³ Barts Health NHS Trust website (accessed October 2019) <https://children.bartshealth.nhs.uk/youth-empowerment-squad>
- ²⁴ Great Ormond Street Hospital for Children NHS Foundation Trust website (accessed October 2019) <https://www.gosh.nhs.uk/teenagers/teengosh-community/young-peoples-forum>
- ²⁵ NHS Digital, *Hospital Accident and Emergency Activity, 2018-19*. September, 2019. <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-accident--emergency-activity/2018-19>
- ²⁶ Royal College of Paediatrics and Child Health, *Facing the Future: Standards for children with ongoing health needs*, March 2018 https://www.rcpch.ac.uk/sites/default/files/2018-04/facing_the_future_standards_for_children_with_ongoing_health_needs_2018-03.pdf
- ²⁷ NHS England, *Interim NHS People Plan*, June 2019. https://www.longtermplan.nhs.uk/wp-content/uploads/2019/05/Interim-NHS-People-Plan_June2019.pdf

-
- ²⁸ NHS Digital, *Health Survey for England 2017*, December 2018.
<https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england/2017>
- ²⁹ Public Health England, *The mental health of children and young people in England*. December 2016.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/575632/Mental_health_of_children_in_England.pdf
- ³⁰ Department of Health Social Care, *The government's revised mandate to NHS England for 2018 to 2019*, March 2018
<https://www.gov.uk/government/publications/nhs-mandate-2018-to-2019>
- ³¹ Department of Health, *Future in mind: Promoting, protecting and improving our children and young people's mental health and wellbeing*, March 2015
<https://www.gov.uk/government/publications/improving-mental-health-services-for-young-people>
- ³² Department of Health and Department for Education, *Transforming Children and Young People's Mental Health Provision: a Green Paper*, December 2017.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/664855/Transforming_children_and_young_people_s_mental_health_provision.pdf
- ³³ Care Quality Commission, *2018 Urgent and Emergency Care Survey*, October 2019.
https://www.cqc.org.uk/sites/default/files/20191023_uec18_statisticalrelease.pdf
- ³⁴ Care Quality Commission, *2018 Adult Inpatient Survey*, June 2019.
https://www.cqc.org.uk/sites/default/files/20190620_ip18_statisticalrelease.pdf
- ³⁵ Care Quality Commission, *2016 Children and young people's inpatient and day case survey*, November 2017.
https://www.cqc.org.uk/sites/default/files/20171128_cyp16_statisticalrelease.pdf
- ³⁶ NHS England website (accessed August 2018)
<https://www.england.nhs.uk/ourwork/safe-staffing/>
- ³⁷ NHS Employers, *Staff Experience and Patient Outcomes: What Do We know?* July 2014.
<http://www.nhsemployers.org/~media/Employers/Publications/Research%20report%20Staff%20experience%20and%20patient%20outcomes.pdf>
- ³⁸ Picker Institute Europe, *Understanding staff wellbeing, its impact on patient experience and health care quality*, June 2015. <http://www.picker.org/wp-content/uploads/2015/06/2015-06-10-StaffWellbeingBriefing.pdf>
- ³⁹ Royal College of Nursing, *Defining staffing levels for children's and young people's services*, August 2013 <https://www.rcn.org.uk/professional-development/publications/pub-002172>
- ⁴⁰ National Quality Board, *Safe, sustainable and productive staffing: An improvement resource for children and young people's inpatient wards in acute hospitals*, June 2018.

https://improvement.nhs.uk/documents/2980/Safe_Staffing_CYP_FINAL_PROOF_27_June_2018.pdf

⁴¹ Care Quality Commission, *The state of health care and adult social care in England 2017-2018*.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/751538/State_of_Care_17-18_web.pdf

⁴² NHS England, *Five Year Forward View*, October 2014.

<https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

⁴³ NHS England website (accessed August 2019)

<https://www.england.nhs.uk/ourwork/part-rel/transformation-fund/bcf-plan/>

⁴⁴ World Health Organisation, *Standards for improving the quality of care for children and young adolescents in health facilities*, 2018.

<https://apps.who.int/iris/bitstream/handle/10665/272346/9789241565554-eng.pdf?ua=1>

⁴⁵ National Institute for Health and Care Excellence, *Transition from children's to adults' services*, December 2016

<https://www.nice.org.uk/guidance/qs140/chapter/Quality-statements>

⁴⁶ Department of Health and Social Care, *The Government's 2019-20 Accountability Framework with NHS England and NHS Improvement*. May, 2019.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/803114/accountability-framework-to-nhse-and-nhsi-2019-to-2020.pdf

⁴⁷ Action for Sick Children website (accessed August 2019)

<http://www.actionforsickchildren.org/childrens-charter/>

⁴⁸ UN, *United Nations Convention on the Rights of the Child (UNCRC)*, November 1989. <https://www.unicef.org.uk/what-we-do/un-convention-child-rights/>

⁴⁹ Department of Health, *You're Welcome – Quality criteria for young people friendly health services*. April, 2011. <https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services>

⁵⁰ NHS Digital website (accessed August 2019). <https://digital.nhs.uk/services/nhs-wifi>

⁵¹ NHS England, *Commissioning Excellent Nutrition and Hydration 2015-2018*, October 2015. <https://www.england.nhs.uk/wp-content/uploads/2015/10/nut-hyd-guid.pdf>

⁵² NHS England, *A toolkit to support NHS commissioners to reduce poor experience of in-patient care*, March 2015.

<https://webarchive.nationalarchives.gov.uk/20161103231959/https://www.england.nhs.uk/wp-content/uploads/2015/04/ip-care-toolkit.pdf>

⁵³ Children and Young People's Health Outcomes Forum, *Report of the children and young people's health outcomes forum*, July 2012.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216852/CYP-report.pdf

-
- ⁵⁴ Wray, J., Hobden, S., Knibbs, S., & Oldham, G. (2018). Hearing the voices of children and young people to develop and test a patient-reported experience measure in a specialist paediatric setting. *Archives of Disease in Childhood*, 103(3). doi:10.1136/archdischild-2017-313032
- ⁵⁵ Tallet, A., & Hopwood, B. (2013). Using a child-friendly survey to obtain feedback about the hospital experience of young inpatients. *Archives of Disease in Childhood*, 98(1). <http://dx.doi.org/10.1136/archdischild-2013-304107.154>
- ⁵⁶ Kamdar, B. B., Martin, J. L., & Needham, D. M. (2017). Noise and light pollution in the hospital: A call for action. *Journal of Hospital Medicine*, 12(10), 861-862. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6629434/>
- ⁵⁷ Fillary, J., Chaplin, H., Jones, G., Thompson, A., Holme, A., & Wilson, P. (2015). Noise at night in hospital general wards: a mapping of the literature. *British Journal of Nursing*, 24(10), 536-540. <https://www.ncbi.nlm.nih.gov/pubmed/26018021>
- ⁵⁸ British Medical Association, *The psychological and social needs of patients*, January 2011. http://bmaopac.hosted.exlibrisgroup.com/exlibris/aleph/a23_1/apache_media/G8KXL7EIUQNLK7RQTQ5EP9ERF4AF1L.pdf
- ⁵⁹ NHS Estates, *Improving the patient experience: Friendly healthcare environments for children and young people*, 2004. <http://www.wales.nhs.uk/sites3/Documents/254/FriendKids.pdf>
- ⁶⁰ National Children's Bureau, *Children, Young People and Health Participation*, 2016. https://www.ncb.org.uk/sites/default/files/field/attachment/cyp_health_participation_final.pdf
- ⁶¹ Annual Report of the Chief Medical Officer, *Our Children Deserve Better: Prevention Pays*, October 2013. <https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays>
- ⁶² Department of Health and Social Care, *The Health and Social Care Act 2008 Code of Practice on the prevention and control of infections and related guidance*, July 2015. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/449049/Code_of_practice_280715_acc.pdf
- ⁶³ NHS Digital, *Patient-Led Assessments of the Care Environment (PLACE) England 2018*, August 2018. <https://files.digital.nhs.uk/A1/6DE37E/PLACE%20-%202018%20-%20report%20v2.pdf>
- ⁶⁴ NHS Digital website (accessed September 2019) <https://digital.nhs.uk/data-and-information/publications/statistical/patient-led-assessments-of-the-care-environment-place>
- ⁶⁵ Hello My Name Is... website (accessed August 2019) <https://www.hellomynameis.org.uk/>

-
- ⁶⁶ The King's Fund, *Making Shared Decision Making a Reality: No Decision About Me, Without Me*, July 2011. <https://www.kingsfund.org.uk/publications/making-shared-decision-making-reality>
- ⁶⁷ Care Quality Commission, *Better care in my hands: A review of how people are involved in their care*, May 2016. https://www.cqc.org.uk/sites/default/files/20160519_Better_care_in_my_hands_FINAL.pdf
- ⁶⁸ National Quality Board, *Safe, sustainable and productive staffing: An improvement resource for children and young people's inpatient wards in acute hospitals*. June, 2018. https://improvement.nhs.uk/documents/2980/Safe_Staffing_CYP_FINAL_PROOF_27_June_2018.pdf
- ⁶⁹ Royal College of Paediatrics and Child Health, *Facing the Future – Standards for acute general paediatric services*. 2015. https://www.rcpch.ac.uk/sites/default/files/2018-03/facing_the_future_standards_for_acute_general_paediatric_services.pdf
- ⁷⁰ CQC website (accessed September 2019) <https://www.cqc.org.uk/help-advice/your-stories/declare-your-care>
- ⁷¹ The Royal College of Emergency Medicine, *Management of Pain in Children*. July, 2017. [https://www.rcem.ac.uk/docs/RCEM%20Guidance/RCEM%20Pain%20in%20Children%20-%20Best%20Practice%20Guidance%20\(REV%20Jul%202017\).pdf](https://www.rcem.ac.uk/docs/RCEM%20Guidance/RCEM%20Pain%20in%20Children%20-%20Best%20Practice%20Guidance%20(REV%20Jul%202017).pdf)
- ⁷² Vittinghof, M. et al. (2018). Postoperative pain management in children: Guidance from the pain committee of the European Society for Paediatric Anaesthesiology (ESPA Pain Management Ladder Initiative). *Pediatric Anesthesia*, 28, 493-506. <https://onlinelibrary.wiley.com/doi/pdf/10.1111/pan.13373>
- ⁷³ Royal College of Surgeons, *Standards for Children's Surgery*, 2013. https://www.rcseng.ac.uk/-/media/files/rcs/library-and-publications/non-journal-publications/rcs_standards_for_childrens_surgery_2013.pdf
- ⁷⁴ Royal College of Surgeons, *Standards for non specialist emergency surgical care of children*, 2015. <https://www.rcseng.ac.uk/library-and-publications/rcs-publications/docs/standards-for-non-specialist-emergency-surgical-care-of-children/>
- ⁷⁵ Department of Health, *Ready to go? Planning the discharge of patients from hospital and intermediate care*, 2010. https://www.sheffieldmca.org.uk/UserFiles/File/Ward_Collab/Ward_Principles/Ready_to_Go_Hospital_Discharge_Planning.pdf
- ⁷⁶ Bernhardson, B., Tishelman, C., & Rutqvist, L. E. (2008). Self-reported taste and smell changes during cancer chemotherapy. *Supportive Care in Cancer*, 16(3), 275-283. <https://link.springer.com/article/10.1007/s00520-007-0319-7>
- ⁷⁷ Royal College of Paediatrics and Child Health, *Policy response for Scotland to the State of Child Health report 2017*, July 2018. <http://www.rcpch.ac.uk/system/files/protected/page/SOCH-recommendations-Scotland.pdf>

⁷⁸ Bureau of health information website (access October 2019).
http://www.bhi.nsw.gov.au/nsw_patient_survey_program/Admitted_Children_and_Young_Patients_Survey

⁷⁹ Toomey, S. L., Elliott, M. N., Zaslavsky, A. M., Klein, D. J., Ndon, S., Hardy, S., Melody, W., & Schuster, M. A. (2017). Variation in family experience of pediatric inpatient care as measured by child HCAHPS. *Pediatrics*, *4*, e20163372
<https://pediatrics.aappublications.org/content/pediatrics/139/4/e20163372.full.pdf>

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