

SURVEY DEVELOPMENT REPORT

CHILDREN AND YOUNG PEOPLE'S PATIENT EXPERIENCE SURVEY 2020

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Updates

Before using this document, please check that you have the latest version, as small amendments are made from time to time (the date of the last update is on the front page). In the very unlikely event that there are any major changes, we will email all trust contacts and contractors directly to inform them of the change.

This document is available from the [page dedicated to the 2020 Children and Young People's Patient Experience Survey on the NHS surveys website](#).

Questions and comments

If you have any questions or concerns regarding this document, or if you have any specific queries regarding the submission of data, please [contact the Survey Coordination Centre for Existing Methods](#) using the details provided at the top of this page.

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1. Introduction

The Children and Young People's Patient Experience (CYP) survey was first undertaken in 2014, as part of the NHS Patient Survey Programme (NPSP). The survey is coordinated by the Survey Coordination Centre for Existing Methods (SCCEM) based at Picker on behalf of the Care Quality Commission (CQC). The 2020 survey is its fourth iteration.

The survey gathers information on children and young people's (aged 15 days to 15 years) patient experiences of care during a hospital admission. This includes both patients who were admitted and stayed in hospital overnight and those who were admitted but did not stay overnight (e.g. emergency and planned day cases).

The sampling period for CYP 2020 covered three months: November 2020, December 2020 and January 2021, which is a longer sampling period than in previous survey iterations (previously sampling in November and December only¹). The extension of the survey sampling period by one month was implemented to offset the negative impact of the COVID-19 pandemic on admission numbers and projected decline in responses to the survey².

The survey involves completion of a paper questionnaire sent by post to the patient's residence and addressed to 'the parent/carer of [child's name]'. There are three separate age-dependent self-completion questionnaires: one for parents/carers of children aged 0 to 7 years old, one for children and young people aged 8 to 11 years old and their parents/carers, and one for young people aged 12 to 15 years old and their parents/carers.

The questionnaires cover topic areas relevant to each stage of the patient's attendance such as their admission, experience on the ward, interactions with staff, involvement in discussions on treatment and care, operations and procedures and the discharge process.

The data collected from the 2020 Children and Young People's Patient Experience Survey will be used by the CQC in its assessment of NHS Trusts in England, NHS England and NHS Improvement (NHS E&I), the Department of Health and Social Care (DHSC) and by individual NHS Trusts to understand patients' experiences and to drive improvements to them.

By conducting this survey and ensuring that organisations carry it out in a consistent and systematic way it is possible to build up a national picture of children and young people's experiences of hospital care, to compare the performance of different organisations, monitor change over time, and identify variations between different patient groups. This rich evidence base will help drive the improvement of children and young people's patient experience in the NHS.

¹ A small number of trusts sample back to October due to low sample numbers.

² It was projected that responses could drop by as much 8000 nationally across the trusts, when compared to 2018 figures, if fieldwork was not extended into January 2021.

1.1 Summary of Development

The survey development process began in August 2020 and was implemented in a number of stages, utilising a variety of different approaches, including:

- Analysis of the 2018 survey data including item non-response, ceiling effects and question correlations and analysis of a sample of open-ended responses to make recommendations for question removal and additions.
- Desk research to review existing literature on policy and frameworks such as the NHS Patient Experience Framework and the NHS Long Term Plan, to ensure that the questionnaires assess new policy processes.
- Gender question redevelopment was conducted to enhance inclusivity. An extensive redevelopment process was conducted including desk research to establish current best practice and to inform the material utilised in the gender stakeholder workshops.
- A young people's focus group to understand the patient journey and the most important factors of the patient experience for young people. Key topic areas such as being listened to, mental health, transitioning to adult services and the impact of COVID-19 were highlighted.
- Advisory Group³ to consider the survey content and proposal of new question items. The Advisory Group consisted of key stakeholders, including NHS trusts, policy makers, research charities and other official bodies. These members are consulted throughout survey development to ensure the questionnaire aligns with current procedures and areas of interest.
- Stakeholder workshops and consultation to design and co-create the gender questions for testing with young people through cognitive interviewing.
- Cognitive testing with children, young people and their parents, who had recently been admitted to hospital to test new questions and fine tune existing questions and cover letters.
- Cognitive testing of the gender questions with young people who identify as cisgender, transgender, non-binary, gender diverse and agender⁴.
- All survey materials were adjusted to adhere to the accessibility requirements of The Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018. This included offering easy read, large print and braille versions of the questionnaires.

³ Advisory Group members represented the following organisations: NHS Youth Forum, Barts Health NHS Trust, NHS England, Clic Sargent, Queen's University Belfast, Great Ormond Street Hospital for Children NHS Foundation Trust, Cornwall CCG, National Institute for Health and Care Excellence, Imperial College London and CQC.

⁴ [Merriam-Webster online dictionary](#),(2021), Cisgender of, relating to, or being a person whose gender identity corresponds with the sex the person had or was identified as having at birth; Transgender, of, relating to, or being a person whose gender identity differs from the sex the person had or was identified as having at birth; Non-binary, relating to or being a person who identifies with or expresses a gender identity that is neither entirely male nor entirely female; agender, of, relating to, or being a person who has an internal sense of being neither male nor female nor some combination of male and female: of, relating to, or being a person whose gender identity is genderless or neutral.

- Taking on board positive results of recent pilot studies in other surveys within the NPSP and applying these approaches to the 2020 CYP Survey in efforts to make the survey more engaging and improve response rates.

1.2 Summary of Changes

The development work resulted in a number of changes to the materials and methods for the 2020 survey. In brief, these are:

- Sample period extension – following analysis of the decline in hospital admissions and projected decline in respondent numbers due to COVID-19, the sampling period for the 2020 Children and Young People’s Patient Experience Survey was extended by one month to include January 2021.
- Questionnaire – a number of questions were added and amended in all three questionnaires to reflect: changes in NHS guidance, policy and circumstances during the Coronavirus (COVID-19) pandemic; the response of the young people’s focus group; the recommendations of the stakeholders groups; and the recommendations of the advisory group.
- Covering letters – the wording was altered slightly to be more approachable, motivating and to incorporate developments across the wider NPSP. Additionally, letters were personalised to clearly specify that the young person and the parent (for 8 to 15 year olds) should complete the questionnaire. The Q&A section of the covering letters were amended to comply with data protection regulations and the availability of easy read, braille and large print questionnaires was referenced. A braille version of the cover letter was also designed⁵.
- Survey manuals – the structure of the sampling instructions was significantly reworked following similar recent changes across other NPSP surveys to improve clarity.
- Dissent (opt-out) posters – following a specific request from a trust, posters were translated into two further non-English languages (Romanian and Kurdish) and made available to trusts in addition to the posters in the other ten most commonly spoken languages in England, including English.
- Added variables to sample files – trusts are asked to submit three new variables to the sample file: a flag of whether the trust hold a mobile phone number for the patient, a COVID-19 diagnosis indicator and a COVID-19 treatment/suspected indicator. The mobile number indicator will help to assess the feasibility of transitioning the survey from a paper-based to a mixed-mode survey (featuring the option to respond on paper or online). While the two COVID-19 variables will allow CQC and the SCCEM to examine whether the experiences of children and young people with confirmed or suspected COVID-19 differ from other children and young people.

⁵ [The Public Sector Bodies \(Websites and Mobile Applications\) \(No. 2\) Accessibility Regulations 2018](#) came into force on 23 September 2018 which means that all public sector websites (and the documents published on them) need to meet certain accessibility requirements.

2. Development of the 2020 CYP Survey

2.1 Background

The last iteration of the survey, the 2018 Children and Young People's Survey (CYP18), was the third survey of its kind conducted by CQC. 129 trusts were evaluated by children, young people and their parents in eight different areas of care: (1) admission to hospital, (2) the hospital and ward, (3) doctors and nurses, (4) facilities for parents and carers, (5) pain management, (6) operations and procedures, (7) leaving hospital, and (8) overall experience. Fieldwork was conducted between February and June 2018, with 33,179 completed questionnaires returned and feedback from 10,927 children and young people. An overall response rate of 25% was achieved.

The brief for the 2020 survey requested that the SCCEM develop and implement a methodology and survey instrument(s) to administer the national 2020 Children and Young People's Survey to all English NHS trusts providing paediatric inpatient and day case services. This methodology was to be based on learnings from CYP18 and the 2019 Children and Young People's Survey Pilot⁶, where appropriate. The stated objectives were to;

- Revise the existing questionnaires, to ensure that questions remain relevant and reflect important emerging topics in children and young people's experiences in NHS hospitals in England.
- Redevelop the gender question, based on learnings from the development of the 2020 Adult Inpatient Survey, recent work conducted by the Office for National Statistics, consultation with the CQC Equality, Diversity & Human Rights (EDHR) group and other external organisations.
- Cognitively test the revised questionnaires with a wide range of children, young people and their parents.
- Develop and cognitively test all necessary supporting materials for the survey, including: cover letters, dissent posters, multilanguage sheets, the information leaflet for children and young people, and any other materials crucial to the successful and ethical implementation of the survey.

The general sampling approach for the 2020 survey remains the same as the 2018 Children and Young People's Patient Experience Survey. Trusts will sample up to 1,250 admitted children and young people, aged between 15 days and 15 years, who were discharged from hospital during the sampling period. This includes both patients who were admitted and stayed in hospital overnight and those who were admitted but did not stay overnight (e.g. emergency admissions and planned day cases). However, for CYP 2020, the sampling period is from 1st November to the 31st January instead of 1st November to 31st December as in previous iterations.

Data collected from the 2020 Children and Young People's Patient Experience Survey will be used by the CQC in its assessment of NHS trusts in England who provide children and young people's services. The data will be made publicly available on the CQC website and will be used where relevant in the CQC programme of reviews and studies. Analyses and aggregate data, such as trust-level results, will also be shared with NHS E&I and the DHSC. NHS E&I will use the results to

⁶ Mixed-mode pilot, carried out in 2020, offering children and young people and their parents the option to complete the survey either online or on paper conducted by the Survey Coordination Centre for Mixed Methods, based at Ipsos MORI on behalf of CQC.

understand patient's experiences of NHS services and to drive improvements to them. They will use the results to generate aggregate indicators at local, regional and national level. Respondent-level data will also be shared with NHS Digital, or other organisations, working on behalf of the DHSC or NHS E&I for the purpose of generating these indicators.

The data collected is also used by individual NHS trusts which provide children and young people's services to identify and develop targeted improvement initiatives to address areas of concern and to highlight where services are performing well compared to others. In terms of the survey itself, the questionnaire is designed to enable NHS trusts to take action on the results. Crucially, the collection of survey data systematically across all trusts allows for comparable data to be obtained. This allows individual trusts to identify areas for improvement in patient's experience and children and young people's services, not only from their own results but also in terms of their position nationally.

2.2 Analysis of the 2018 CYP Survey Data

Analysis of the 2018 survey data including item non-response, ceiling effects and question correlations were completed to highlight potential questions for removal. Item non-response refers to questions that were not answered (i.e. left blank) but were applicable to the respondent. A high level of non-response on a particular question may indicate that either respondents do not understand the question, the question is not relevant to them, that not all possible response options are listed or something else. Ceiling effects are when a question is answered the same by nearly all respondents. For instance, if 95% of respondents answered yes to a question then this can be an indication that the question may not provide useful insight. Question correlations are conducted to identify any questions that are statistically similar to one another. This may lead to questions being removed if several questions appear to be measuring the same thing.

Analysis of a sample⁷ of the open-ended responses was conducted, to establish if any questions needed to be amended or added. All three surveys provide space for the parent and the child or young person (8-15 years questionnaires) to provide written open-end feedback on their experience.

Feedback from the 2018 cognitive interviews was also reviewed to establish if any questions performed poorly (i.e. a considerable percentage of respondents found them difficult to understand).

Ceiling/floor effects

The performance analysis identified some potential items for consideration with regards to ceiling and floor effects. Whilst this analysis can help to identify items that may require revision, it alone does not determine whether an item should be removed from the questionnaire.

Parent questions

- Q15. Did a member of staff agree a plan for your child's care with you?

This question within the 'Hospital Staff' section displayed a ceiling effect across all three questionnaires with high proportion of parents saying they did agree a plan for their child's care with a member of staff: 91% of parents of children aged 0 to 7 said 'Yes', 92% of

⁷ 5% of open-ends from each comment type (i.e. 5% of parents and 5% of children and young people) were analysed.

parents of children aged 8 to 11 said 'Yes' and 92% of parents of young people aged 12 to 15 said 'Yes'. This positive finding was also shown within the 2016 results.

Children questions

- Q56. Did you feel able to ask staff questions?

This question has a large ceiling effect: 93.8% of children aged 8 to 11 answered 'Yes' they felt they were able to ask staff questions. This ceiling effect was also observed for children aged 12 to 15, with 95.6% selecting 'Yes'. Additionally, the following filtered question, Q57, 'Did the hospital staff answer your questions?' also displayed ceiling effects across both for children aged 8 to 11 (91.4% selected 'Yes') and young people aged 12 to 15 year olds (92.6% selected 'Yes'). This finding is consistent with previous years, where in 2016 a ceiling effect was also found.

Correlations

There were a number of correlations between questions⁸, particularly in the 0-7 years questionnaire. However, although strong, they did not meet conventional criteria for redundancy (e.g. $r > .80$, $.90$)⁹. As such, questions were not considered for removal by the advisory group on the basis of correlations with other questions.

Non-Specific Response

Parent questions

- Q27. Did your child like the hospital food provided?

49.6% select 'My child did not have hospital food'. Great Ormond Street Hospital (GOSH) have noted the importance of good nutrition for sick children in their Food and Nutrition project which addresses raising awareness of their Trust Nutrition Policy¹⁰. Additionally, the Department of Health and Social Care (HSC) announced in August 2019 a review of hospital food¹¹, ensuring quality food is delivered to aid faster recovery with new systems to monitor food safety.

- Q29. Were you able to prepare food in the hospital if you wanted to?

In the questionnaire for young people aged 12 to 15, 50.8% of parents said 'I did not want to prepare food', when asked 'Were you able to prepare food in the hospital if you wanted to?'. A high proportion of non-specific response was also observed for parents of children aged 8 to 11, with 48.1% responding 'I did not want to prepare food' and parents of children aged 0 to 7, with 47.1% selecting this response option.

Review of Free Text Data

A review of a sample of the free text data submitted from parents and children and young people was conducted to identify any possible themes that could be included as question items within the

⁸ Parents 0 to 7 year olds: Q16 with Q42, Q17 with Q18, Q44 with Q42, Q16, Q43, Q46, Q47, Q47 with Q46, Q45, Q42, Q25, Q16. Children 8 to 11 years old: Q69 with Q70. Children 12 to 15 years old: Q69 with Q70

⁹ Patten, M.L, and Newhard, M., (2017), The Pearson Correlation Coefficient (r) in Understanding Research Methods, Routledge, 10th Edition.

¹⁰ Great Ormond Street Hospital, (n.d.), Food and Nutrition Project, <https://www.gosh.nhs.uk/parents-and-visitors/food-and-nutrition-project/>

¹¹ Department of Health and Social Care, (2019), Hospital food review announced by government, <https://www.gov.uk/government/news/hospital-food-review-announced-by-government>

questionnaire(s). Many common themes were explored and the mental health theme was subsequently developed into a question for testing during questionnaire development. The lack of provision of mental health support for children and young people whilst in hospital was specifically mentioned by children and young people. There is no question about the provision of mental health support in the questionnaire but children and young people were asked about whether they could talk to a member of staff about their worries/fears.

Feedback from 2018 Cognitive Testing Interviews

Reviewing the 2018 cognitive interview notes uncovered one question whose meaning wasn't understood correctly by a minority of respondents. The question Q23 'Did you feel that staff looking after your child knew how to care for their individual or special needs?' was understood by some respondents to mean 'special needs' such as a long term condition or disability. As such these parents believed that the question did not apply to their child. The question aimed to capture if staff understood the child's specific or individual needs. Additionally, during cognitive testing in 2018 children, young people and their parents/carers were thinking of a range of different things in response to the 'operations and procedures' question ('During their stay in hospital, did your child have any **operations or procedures**?'). Participants responded that they had an operation or procedure if they/their child had a blood test, scan or x-ray. These are outside of the NHS data dictionary definition of a 'procedure'¹². As a result, a note, '**Please do not include blood tests, scans or x-rays**' was added for the 2020 survey.

3. Patient Experience Framework (PEF)

The [NHS Patient Experience Framework](#) is used by the DHSC, and was adopted by the NHS National Quality Board (NQB) to guide the measurement of patient experience across the NHS.

The NHS Patient Experience Framework was adopted by the NQB and built on a modified version of the Picker Institute Principles of Person Centred Care. The main themes within the framework are:

- Respect for patient-centred values, preferences and expressed needs
- Physical comfort
- Coordination and integration of care
- Information, communication and education
- Emotional support
- Welcoming the involvement of family and friends
- Transition and continuity
- Access to care

For the most part, the current questionnaires content aligned relatively well with the overall themes of the framework. Respect for patient-centred values, preferences, and expressed needs is covered by questions on privacy ('Were you given enough privacy when you were receiving care

¹² NHS, (n.d.), NHS Data Model and Dictionary, https://datadictionary.nhs.uk/nhs_business_definitions/patient_procedure.html#business_definition_patient_procedure.description

and treatment?') and involvement in decision making ('Were you involved in decisions about your care and treatment?'), for example. Framework items such as the coordination of care and physical comfort are specifically addressed through questions on leaving hospital ('When you left hospital, did you know what was going to happen next with your care?'), and pain management ('If you felt pain while you were at the hospital, do you think staff did everything they could to help you?'). Parents and caregivers are asked about their level of involvement ('Did staff involve you in decisions about your child's care and treatment'), and transitions are addressed with the section 'Leaving Hospital'.

However, the parent's questionnaire (for children aged 0 to 7) was lacking on items that focus on **emotional support**. While there was an item for parents on staff caring for their child listening to them, there was not an item that covers whether, if parents had any worries or fears, they were able to discuss them with a member of staff. A question on emotional support was asked within the children and young people's questionnaires ('If you had any worries, did a member of staff talk with you about them?'), however it could be an extremely stressful time for the parent or carer, and they may also wish to discuss their anxieties or worries about their child's condition or treatment with a member of staff.

The **access to care** theme was found to be absent from the parent's section of the questionnaires for both children aged 8 to 11 and young people aged 12 to 15. While the questionnaire for children aged 0 to 7 includes additional items for planned admissions — specifically, on whether they had been given a choice of admission dates and whether the hospital changed their admission dates — questions like these were missing from the parent section of the other two questionnaires. Given that planned admissions were likely to have been impacted in response to the COVID-19 pandemic, it could be important to capture whether parents were given an option of admission date and how many of these appointments were then amended, across all three of the questionnaires.

4. Policy and the Children and Young People's Patient Experience Survey

A range of changes in policy and NHS guidance were relevant for the development of the 2020 Children and Young People's Patient Experience Survey. These were changes due to the COVID-19 pandemic and aspects highlighted in the NHS Long Term Plan.

NHS Long Term Plan

The NHS Long Term Plan, published in January 2019, sets out key areas of focus for NHS England. The NHS Long Term Plan highlights areas of children and young people's care that will be improved. Some of these main areas are discussed below:

- 25% of emergency admissions are children and young people, who are the most likely age group to attend unnecessarily with many conditions being treatable in primary or community care settings. The plan discusses local areas implementing models of care for appropriate ages, bringing together physical and mental health services.
- Access to paediatric critical care and surgical services closer to home. A coordinated care approach will enable access to urgent, emergency and planned services. This will see the involvement of hospitals, NHS staff, patients and their families to ensure this approach is implemented effectively.

- Continuity of care for children and young people. Currently, children aged 12 can be transferred to adult services, leading to poorer health outcomes if their transition is not managed adequately. By 2028 the NHS aims to roll out person-centred and age appropriate care which concentrates on the care need rather than an arbitrary transition to adult services based on age.

COVID-19 Impact on Children and Young People's Services

The NHS within England has faced a considerable challenge in response to the impact of the COVID-19 pandemic. Children and young people have lower rates of hospitalisation and severe hospitalisation than the adult population¹³¹⁴, however the burden and pressure that the pandemic has placed on the NHS has impacted the majority of services offered by the health service.

Our research highlighted seven broad areas of change for paediatric services in response to the first wave of the pandemic: the use of Personal Protective Equipment (PPE), introduction of cohort areas, temporary pauses on elective surgery, facilities for parent/carer, play facilities for children, and the visiting and involvement of parents and carers.

A question was designed to capture the latter theme, the visiting and involvement of parents and carers — 'Were you able to be with your child as much as you needed to?' (see section 9, below, for more information). Paediatric patients are still permitted to be accompanied by a parent or carer, but during the survey development this was limited to only one accompanying person¹⁵. For inpatients, the accompanying parent or carer visiting hours were not limited, but it was not clear whether restrictions were in place for the parent or carer being able to stay overnight. It is anticipated that whilst overnight stays are still in place for paediatric inpatients, there is local variation as to what this looks like in practice and that it remains under the jurisdiction of each trust to determine if and when those facilities are scaled back. The 2018 survey included a question for parents as to whether they were able to stay overnight with their child whilst in hospital.

5. Young People's Focus Group

A young person's focus group was conducted on 25th August 2020 with young people recruited from a young people's patient's forum. The young people recruited for the group are long standing members of NHS children's services patient forum with a wealth of experience and understanding of those services. Including young people was important to ensure that their voices and concerns were listened to, understand the patient journey from their point of view and establish the most important factors of the patient experience for them. Key topic areas such as being listened to, mental health, transitioning to adult services and the impact of COVID-19 were highlighted and brought forward to the advisory group for consideration.

¹³ BMJ, (2020), Clinical characteristics of children and young people admitted to hospital with covid-19 in United Kingdom: prospective multicentre observational cohort study, <https://www.bmj.com/content/370/bmj.m3249>

¹⁴ European Centre for Disease Prevention and Control, (2020), COVID-19 in children and the role of school settings in transmission - first update, <https://www.ecdc.europa.eu/en/publications-data/children-and-school-settings-covid-19-transmission>

¹⁵ NHS, (2020), Visiting healthcare inpatient settings during the COVID-19 pandemic: principles, https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0751-visiting-healthcare-inpatient-settings-principles-131020_.pdf

6. Advisory Group

The advisory group met on 2nd September 2020 and were provided questionnaires to review prior to and following cognitive testing. The advisory group members represented key stakeholder organisations, including; NHS Youth Forum, Barts Health NHS Trust, NHS E&I, Clic Sargent, Queen's University Belfast, Great Ormond Street Hospital (GOSH), Cornwall Clinical Commissioning Group, The National Institute for Health and Care Excellence (NICE), Imperial College London and CQC.

The SCCEM presented the findings from the 2018 data analyses, current policy guidelines and frameworks and the results of the young people's focus group to advisory group. Members provided feedback and recommendations on new potential questions, how to formulate questions and recent policy changes¹⁶.

Following the Advisory Group Meeting, the below question themes were agreed to be taken forward for further discussion, development and appraisal by CQC and the SCCEM:

- COVID-19 and PPE – there was agreement that the 2018 questionnaire content and topics are still relevant in the context of COVID-19 and there would be no need for a COVID-19 focused questionnaire. The young people's focus group discussed PPE and ways to make it friendlier for younger children. Participants reflected on how staff in PPE might make children feel, and ways that this could be mitigated. The advisory group noted that there may be some differences between trusts in steps taken to ensure that PPE is 'child friendly' and PPE was brought forward as a topic for question development.
- Visitation and facilities for parents – a review of policy suggested that paediatric patients were still permitted to be accompanied by a parent or carer, but this was limited to only one person. It did not appear that visiting hours or overnight stays had been restricted but it was unclear if there was local variation. Questions around the involvement of parents was considered crucial in order to understand trusts adoption of COVID-19 safety measures.
- Emotional wellbeing and mental health – questions on the mental and emotional health of children and young people were considered important by both the advisory group and the young people's focus group. The questionnaire included a question about worries ('If you had any worries, did a member of staff talk with you about them?') but specific emotional and mental health questions were absent.
- Individual needs – the questionnaire included a question in the parent's section which asked whether they felt that their child's specific needs were cared for. This question was designed to capture support of all needs, including mental health or emotional needs ('Did you feel that staff looking after your child knew how to care for their individual or special needs?'). During cognitive testing in 2018 some parents interpreted the question as meaning 'special needs' such as long-term condition or disability and it was agreed by the advisory group that the wording should be adjusted to better reflect the intended meaning.
- Transitioning to adult services – the young people's focus group and advisory group felt that transitioning to adult services was an important issue to address in the 2020 questionnaire. Reflecting the age of the respondents (12 to 15), the focus of the question

¹⁶ The advisory group was not involved in the initial stages of the gender question development as the gender stakeholder group had provided excellent direction and insight into best practice.

would be to establish if young people received information or were happy with information they received about transitioning.

- Speaking up – the questionnaire included questions on whether young people felt that they could talk to staff ('Did you feel able to ask staff questions?'), however the advisory group believed that the focus should move from being able to voice concerns to understanding if children and young people felt listened to by staff.
- Food – food was an area highlighted as important by the young people's focus group and advisory group members. The 2018 questionnaire included a question on whether children and young people liked the hospital food, however it was noted that other important food related topics were not covered i.e. quality of food, if it was healthy, if they had choices and if dietary options (vegan, vegetarian, gluten free) were offered.
- Consent – the advisory group suggested including a question to establish if consent was sought from children and young people, with draft wording 'did children have their say about what was happening in hospital'.

Both the children and young people focus group and the Advisory Group did not wish for any of the existing questions to be removed, which meant that there was limited space for new items. Questions about food, consent and PPE were not taken forward for development as support (among the advisory group) was weaker than for the other questions. After careful design and deliberation, four new questions were included for Round 1 of cognitive testing. Please see section 9 for details.

7. Redevelopment of the Gender Question

In recent years a number of policies have come into force which are committed to tackling issues related to gender identity¹⁷. The CQC, as part of their remit, equality and human rights approach and their equality objectives 2019-2021, is dedicated to ensuring that equalities are central to regulatory work.

In light of these objectives, CQC commissioned the SCCEM to revise the sex/gender question. A number of steps and consultations, detailed below, were undertaken prior to and during cognitive testing in the development of the new gender questions.

Desk Research

CQC and the SCCEM conducted desk research to understand current best practice, the latest academic research and other large scale national survey approaches (such as approaches in ONS surveys, the upcoming census, Stonewall's 2017 survey 'The experiences of lesbian, gay, bi and trans young people in Britain's Schools', Sport England's recurring 'Active Lives' survey. The key finding from this desk research was that only two large-scale surveys had featured response options in addition to 'male' and 'female' for gender questions for children and young people: the most recent version of the Active Lives survey had given children and young people the opportunity to self-describe and the Stonewall survey had given children and young people the

¹⁷ Government Equality Office, (2018), LGBT Action Plan 2018: Improving the lives of Lesbian, Gay, Bisexual and Transgender people, <https://www.gov.uk/government/publications/lgbt-action-plan-2018-improving-the-lives-of-lesbian-gay-bisexual-and-transgender-people>

opportunity to self-describe, a 'prefer not to say' option, and a follow up question 'do you identify as trans?'.

Stakeholder Workshops

The results of the desk research were used as discussion materials in the stakeholder workshops¹⁸, which were conducted with organisations working closely with gender diverse young people. Two separate workshops were held to help inform the development of gender questions suitable for young people under the age of 16. The recommendations from the stakeholder workshops guided the design of the gender questions brought forward to the cognitive testing stage. The key findings from the stakeholder groups were that:

- Two questions are required to sensitively establish if someone has a transgender history, as many will not state this in an open-ended box. The questions required are the current gender they identify with and their 'sex assigned at birth'.
- Gender should be asked first as this is how the person identifies now, while sex should be secondary. The wording 'sex assigned' or 'sex given' at birth is very important to prevent any connotations that their 'real' sex is the one with which they were born.
- Young people should be provided the opportunity to self-describe or describe their gender in their own words through the inclusion of an open-ended box.
- The questions should be voluntary and young people should be afforded the opportunity to 'prefer not to say'.

Questions utilised in cognitive testing, along with the final questions included in the questionnaires, can be found in section 9.5.

8. Cognitive Testing

Considering all of the evidence from the summary report and feedback from the advisory group, a questionnaire was drafted for cognitive testing. 'Cognitive testing' involves interviews with relevant participants and asking them to answer the questionnaire, reading out loud and explaining the reasoning behind their answers. The interviewer observes the responses that the participant makes and periodically asks questions such as whether the question was easy to answer, what their circumstances were and what they were thinking about when considering their answer. The interviewer also pays attention to whether the respondent appears to struggle when answering certain questions, and whether instructions were read and followed correctly. Cognitive testing ensures that as far as possible, the instructions, questions and response options are relevant and understood. For this survey the covering letters were also tested since they had undergone changes since the previous survey. Refinements are made to the survey materials following each round of testing in accordance with any issues that are evidenced by the interviews.

Cognitive interviews were conducted from 28th September 2020 to 9th November 2020 via phone or video conference rather than face-to-face as in 2018, due to current social distancing regulations in

¹⁸ Representatives from Mermaids (supports gender-diverse children and young people until their 20th birthday), SAYiT (a lesbian, gay, bisexual, trans plus (LGBT+) young people charity) and Medway Gender Sexual Diversity Centre (provides services for LGBTQI+ people their families and friends) as well as representatives from the CQC Equality, Diversity and Human Rights Division took part. A number of other organisations provided feedback through email including GIDS (Gender identity development service), LGBT Foundation, Pink Therapy and Gendered Intelligence.

the context of COVID-19. Conducting the interviews virtually allowed researchers to conduct interviews across a larger geographical spread, without the necessary travel time. Copies of materials (appropriate questionnaire, cover letter, information leaflet and consent forms) were emailed to the participants in advance of the interview (though respondents were asked not to read the questionnaire in advance).

The cognitive testing process involved three distinct approaches:

- Main stage cognitive testing with children and young people, and their parents (18 children and 18 parents), who had been an inpatient in hospital in the last six months.
- Gender question cognitive testing with non-cisgender or gender diverse young people aged under 18 years. The SCCEM conducted 8 cognitive interviews with non-cisgender and gender diverse young people focusing on four different versions of the gender question (designed in the stakeholder groups).
- Top-up gender question interviews with 10 more cisgender 12 to 15 year olds (were not required to have been in hospital in the last 6 months) to establish broader understanding and acceptability of the final version of the gender question.

8.1 Recruitment

Main Stage Recruitment Approach

Adults (parent/carer) and children and young people (8 to 15 year olds) were recruited for cognitive interviewing on the basis that the child/young person had recently been admitted as either an inpatient or day case to an NHS Hospital in England. We aimed to speak to those who had the most recent hospital visits but all had visited within the last six months. This reflects the maximum time between the sampling month and when the patient would be expected to receive the questionnaire under normal circumstances in the main survey so that recall of events is comparable.

Recruitment for cognitive testing aimed to achieve a mix of demographic characteristics. During recruitment, we screened prospective interviewees to ascertain a child's/young person's and, by extension, the corresponding parents/carers eligibility to be interviewed. To do this the following information was gained in relation to the child/young person: age, hospital visited, date of visit, reason for visit, and length of stay (if applicable).

In addition, we also asked the following questions to help ensure we were able to interview individuals with a mix of demographic and geographic characteristics to account for different patient experiences: gender, ethnicity, route of admission (emergency or planned), nature of any long-term conditions (including any accessibility issues) and geographic location.

As no recruitment on site could take place this year¹⁹ as a consequence of the COVID-19 pandemic, we aimed to diversify recruitment across a range of channels, predominantly online, to reach as many respondents as possible. The following venues/sources were used to place recruitment adverts:

- Local Papers (online) – Adverts were placed in the Oxford 'Daily Info' and the Manchester Evening News.

¹⁹ In 2018, 35 out of the 36 interviews were achieved by recruiting on site via three NHS trusts: Great Ormond Street, John Radcliffe in Oxford and Bristol Children's Hospital.

- Gumtree – Free ads were placed in 20 locations across the UK.
- Social Media (Facebook/Twitter/LinkedIn) – The recruitment advert was promoted on the Picker Facebook Page. Picker colleagues were also be asked if they are willing to share via their own social media accounts to aid a wide geographical spread. Facebook ‘boosted posts²⁰’ were also utilised, but did not generate much interest.
- NHS trusts – A selection of NHS trusts were also asked to share our advert on their social media accounts. This was the most fruitful recruitment strategy.

Gender Questions Recruitment Approach

Children and young people were recruited based on their identification as non-binary, transgender or they are unsure or use a different label. They did not need to have been in hospital in the last 6 months as only the gender question options were discussed.

Recruitment focused on LGBT+ and gender diversity support organisations. Recruiting through a trusted organisation helped to encourage participation and assure young participants of the legitimacy of the research. The SCCEM contacted 47 of these organisations across the UK, sourced through google searches and Tranzwiki²¹. Twelve²² organisations posted the advert on their social media, website or shared with their network. The SCCEM also attended a SAYiT²³ online group meeting with young people to describe the research and invite participation. Taking a direct personal approach to recruitment through partner organisations, whereby the interviewer meets the group of young people to explain the research and invite their participation offered the opportunity for young people to ask questions in a safe environment prior to agreeing, or not, to take part.

This cohort of young people were particularly challenging to recruit. The initial incentive offered was £25 but this was increased to £40 considering the difficulty accessing this small sub-section of young people. Another key challenge was the requirement for parental consent. The SCCEM require parental consent for anyone under 16 years to take part in the research, along with the young person’s consent, as per the MRS guidelines. We found that the requirement for parental consent did in fact hinder recruitment and thus the SCCEM and CQC made the decision to extend the age range up to 18 years.

Top-Up Gender Question Recruitment from General Population (age 12-15)

Prior to the final round (3rd round) of main stage cognitive testing, the results of the gender question cognitive testing found that this cohort preferred question wording that had not yet been tested with cisgender children and young people. To ensure the question was thoroughly tested for comprehension and ease of completion among the 12 to 15 age group, the SCCEM recruited 10

²⁰ Facebook Boosted Posts are paid advertisements that enable you to set parameters to target the audience we wish to recruit, by selecting criteria based on specific demographics and locations. With access to analytics and the ability to manage the posts once live, you can track the performance of the boosted post and alter parameters as required.

²¹ Tranzwiki (<https://www.tranzwiki.net>) is a comprehensive directory of the groups campaigning for, supporting or assisting trans and gender non-conforming individuals, including those who are non-binary and non-gender, as well as their families across the UK. It has been developed by GIRES to support the trans community but its content is determined by a broad range of stakeholders.

²² Sayit, Porchlight, MGSD, Mermaids, Stonewall, Diversity Role Models, York LGBT Forum, LGBT Plus Notts, Leicester LGBT centre, The Kite Trust, LGBT Foundation.

²³ SAYiT are a lesbian, gay, bisexual, trans plus (LGBT+) young people charity.

young people aged 12 to 15 to test the gender question. They did not need to have been in hospital in the last 6 months as only the gender question options were discussed.

Each interview lasted 10 minutes and was conducted over the phone or via video call. Participants were recruited through the following means:

- Picker staff – Sent out an all staff email to ask Picker staff if they know of anyone who has, or knows, a young person age 12 to 15.
- Local paper – The Oxford ‘Daily Info’ paper was successful in recruiting for the main stage testing.
- Cognitive testing participants/snowball – young people who had previously taken part in cognitive testing for the main stage were asked to take part. In addition, we asked them if they had a friend or family member who could also take part.
- Social media – The advertisement was posted to the Picker website and ‘boosted’ to be viewed by parents across the UK.

8.2 Interviews

Main Stage

As shown in table 1 below, three rounds of testing were carried out with 12 respondents per round. Feedback from the preceding round informed any changes to the questionnaire for the next round. Thirty-six interviews were carried out, with 12 interviews per round of testing, split between the different age groups.

Table 1 Cognitive Testing

Questionnaire	Round 1		Round 2		Round 3	
	Children and young people	Parent/carer	Children and young people	Parent/carer	Children and young people	Parent/carer
0-7	N/A	2	N/A	2	N/A	2
8-11	3	2	3	2	3	2
12-15	3	2	3	2	3	2
Total	6	6	6	6	6	6

Each interview lasted around an hour and a £40 ‘Love to shop’ or ‘Amazon’ voucher was given as a thank-you for taking part. In line with the NPSP, the value of this voucher was increased from £25 in 2018, given the additional barriers in place due to social distancing in the context of COVID-19, to help encourage participation.

Below is a summary of the demographics of participants in cognitive testing.

- Age: A total of eighteen parents were interviewed, six parents of a child aged 0 to 7 years, six parents of a child aged 8 to 11 years and six parents of a young person aged 12 to 15 years. A total of eighteen children and young people were interviewed, nine aged 8 to 11 years and nine aged 12 to 15 years.
- Gender: Seven of the parents interviewed were female and eleven were male. Six of the children interviewed were female and twelve were male.

- Ethnicity: Twenty four participants were White, six Asian and six did not specify their ethnicity.
- Type of Admission: Thirteen children and young people were categorised as emergency hospital admissions, while five children and young people experienced planned hospital admissions.
- Long-term conditions: Seven children and young people had a long-term condition, eleven did not.
- Locations: Participants were based across the UK, in Oxford, Birmingham, Stoke-on-Trent, Scunthorpe, North Devon, Liverpool, Cheshire, and Barnsley.

Gender Question

The SCCEM recruited eight children and young people aged 18 or under who identify as transgender, non-binary, agender or another non-cisgender. Each interview lasted 30 to 45 minutes and a £40 'Amazon' voucher was given as a thank-you for taking part.

Two young people provided feedback through email as they did not feel comfortable speaking to an interviewer over phone or video. The SCCEM and CQC agreed to allow this approach following consultation with organisations that work with gender diverse young people. The advice provided was to offer a text/instant message option for young people to provide feedback but in this instance email was preferred by the two young people. Please see Appendix 1.0 for the questions that were discussed. Participants ranged in age from 13 to 18 years old. Gender identity described by participants included transgender, non-binary and unsure.

Top-Up Interviews

The SCCEM recruited 10 cisgender young people aged 12-15 years to take part in top-up interviews. All interviews took 15 minutes and focused solely on testing three iterations of the gender question to establish understanding and preference. Please see table 4 for questions tested. Participants were aged between 13 and 15 years old, 4 identified as male, 6 as female.

9. Changes to the Questionnaire

9.1 Summary of Changes

A number of changes were made to the Children and Young People's Patient Experience Survey questionnaire for 2020. One new question was added to the 0 to 7 parent/carer questionnaire, two new questions were added to the children's (8 to 11) questionnaire, and three new questions were added to the young people's (12 to 15) questionnaire. The wording of one question was amended, and three notes were added, in all three questionnaires. Additionally, gender questions were redeveloped and modified in the parent/carer 0 to 7 questionnaire, the parent/carer and children's sections of the 8 to 11 questionnaire and the young person's section of the 12 to 15 questionnaire. No questions were removed.

9.2 Questions Removed

There were no questions removed from the CYP18 questionnaire in the development of the CYP20 survey. Feedback from the advisory group was that the existing questions remain important and relevant, particularly this year to ensure quality of care during the COVID-19 pandemic.

9.3 Questions Unsuccessful in Cognitive Testing

The advisory group and young people's focus group were eager to include a question that captured whether children and young people's emotional and mental health needs were being catered to, along with their physical health needs.

The SCCEM and CQC designed three iterations of the emotional wellbeing and mental health question, testing a new version in each round of cognitive testing. However, each iteration did not perform well and the question was excluded from the final questionnaire.

Round 1

Parent's Question: Did the hospital staff talk to your child about their emotional wellbeing or mental health?

Children and Young People's Question: Did the hospital staff talk to you about your emotional wellbeing or mental health?

Feedback from cognitive testing was that this question is not applicable for the younger age groups as parents considered talking about mental health or emotional wellbeing to be their role and children and young people didn't think it was within hospital staff's remit.

Mental health was understood to mean depression or anxiety by both parents, children and young people. Overall the terms were too broad to be consistently understood in the same way.

Round 2

Parent's Question: Did the hospital staff talk to your child about their feelings or emotions?

Children and Young People's Question: Did the hospital staff talk to you about your feelings and emotions?

Parents of children aged 0 to 7 felt this did not apply as their children were too young to have emotional or wellbeing conversations.

Children and young people perceived this question to be concerning worries about being in hospital or worries about their physical injury rather than mental health. Additionally, because children and young people were often thinking of worry related to their hospital stay, a number commented during cognitive testing that it felt similar or the same as question 12 ('If you had any worries, did a member of staff **talk with you** about them?').

Round 3

Parent's Question: Did the hospital staff talk to your child about their emotional wellbeing or mental health?

Children and Young People's Question: Did the hospital staff talk to you about your mental health?

This version was understood by parents of 12 to 15 years olds to some degree. But the term was still considered too vague and they struggled to understand what mental health was in relation to, for example feelings about being in hospital or more generally. Parents of younger children did not feel it was relevant to their child.

Those aged 12 to 15 years understood the question to some extent but were mostly thinking about mental health in the context of their hospital visit. Those aged 8 to 11 years did not understand the concept of mental health with one participant stating 'I don't know what this is'.

The question was not included in the final questionnaire due to the lack of applicability for the 0 to 7 age group, lack of understanding for the 8 to 11 age group and inconsistent interpretation among the 12 to 15 age group.

9.4 Questions Added

One new question was added to the 0 to 7 parent/carer questionnaire, two new questions were added to the children's 8 to 11 questionnaire, and three new questions were added to the young people's (12 to 15) questionnaire. The new questions cover the topics of visitation, staff listening and transitioning to adult services.

Visitation

One question was added to the 0 to 7 parent/carer questionnaire (Q12) and to the parent/carer section of the 8 to 11 (Q30) and 12 to 15 (Q33) questionnaires. This question was added to measure the impact of COVID-19 restrictions on visitation of parents/carers. This question was well understood by parents/carers in all rounds of cognitive testing. They answered based on their own experience of being with their child in hospital during x-rays and tests, with most 'always' able to be with their child.

Q. Were you able to be with your child as much as you needed to?

- Yes, always
- Yes, sometimes
- No
- Don't know/not applicable

Listening

Another question was added to the 8 to 11 (Q11) and 12 to 15 (Q11) questionnaires. During the advisory group meeting there was support for a question about staff listening to children and young people, and patients feeling their worries and concerns were listened to. The question was well understood by children and young people in all rounds of cognitive testing. They considered things such as whether their questions were answered as evidence that staff were listening and whether they 'took in the information'. They also looked for evidence that they were listened to in the staff's actions - they followed up and 'kept checking in'.

Q. When you spoke to hospital staff, did they listen to what you had to say?

- Yes, always
- Yes, sometimes
- No
- I did not speak to hospital staff

Transitioning to Adult Services

One question (Q24) and an accompanying note on transition of care to adult services was added to the young people's (12 to 15) questionnaire only. This question was added following the advisory group and feedback from the young people's focus group, where there was strong

support for capturing young people's readiness for a transition in their care. Additionally, management of the transition of care is a critical element within the NHS Long Term Plan. The question was well understood during cognitive interviewing, with young people easily able to identify whether or not the question applied to their situation.

This question might be important for children and young people that frequently visit hospital for ongoing care. You may not need to answer it.

Q. If you are moving to adult services, did hospital staff give you enough information about what will happen?

- Yes
- Sort of
- No
- I'm not moving to adult services

9.5 Questions Modified

The wording of one question was amended, and three notes were added, in all three questionnaires. Additionally, gender questions were redeveloped and modified in the parent/carer 0 to 7 questionnaire, the parent/carer and children's sections of the 8 to 11 questionnaire and the young person's section of the 12 to 15 questionnaire.

Staff Caring for Child's Needs

The words 'special or individual' was removed from the question on caring for children's needs (2018 question wording 'Did you feel that staff looking after your child knew how to care for their individual or special needs?') in the parent/carer's questionnaire (Q24), and in the parent/carer section of the children (Q39) and young people's questionnaires (Q42). Previously, a small number of parents/carers did not think this question applied to their child as they focused on 'special needs'. They took special needs to refer to a long term condition or disability, and so if their child had neither of these they did not feel it applied to them. In 2018, 16.4% of parents/carers (across all three questionnaires) selected 'don't know/ not applicable'.

The amendment resulted in parent/carers thinking of a wide range of needs when answering this question in cognitive testing. For example, some of the needs mentioned were dietary conditions, learning difficulties, allergies and emotional needs.

Q. Did you feel that staff looking after your child knew how to care for their needs?

- Yes, definitely
- Yes, to some extent
- No
- Don't know / not applicable

Operations and Procedures

A note was added to the operations and procedures question (Q34) in the parent/carer questionnaire (0 to 7), and to the parent/carer and children/young people's sections of the 8 to 11 (Q15 and Q48) and 12 to 15 questionnaires (Q16 and Q51). This note was added during cognitive testing following confusion amongst participants about what should be considered a procedure. Prior to the addition of a note, participants were answering 'yes' to this question for a variety of diagnostic treatments while in hospital, for example, blood tests, X-rays and scans but according to

the NHS Data Dictionary these tests should not be considered a procedure²⁴. The addition of a note to this question worked well during cognitive testing, with participants answering according to instruction.

Q. During your time in hospital, did you have any **operations or procedures**?

Please do not include blood tests, scans or x-rays.

- Yes
- No

Demographics Note

A note was also added to the beginning of the demographic information 'About Your Child' section of each questionnaire, which is answered by parents/carers. This note will allow respondents to understand how the information they provide will be used to evaluate quality of care. This note was added following questions during cognitive interviews about the use and purpose of the demographic information parent's/carers were providing about the child.

ABOUT YOUR CHILD

The following questions will help us to understand how experiences vary between different groups of the population.

Gender Questions

The CYP20 gender questions have been redeveloped as part of CQC's regulatory role to improve equality for everyone. In 2018 the CYP questionnaires asked the respondents gender (or child's gender where the parent/carer is completing the survey for those aged 0 to 7) with response options consisting of 'boy' or 'girl' for those aged 8 to 11 and 'male' or 'female' for those aged 12 to 15 and parent/carers of those aged 0 to 7.

In redeveloping the gender question, the SCCEM undertook a number of phases of consultation, including desk research, stakeholder workshops, and cognitive Interviews with both cisgender and non-cisgender young people.

0 to 7 Questionnaire

Following consultation with the gender stakeholder groups the below questions were included in round 1 of cognitive testing.

²⁴ According to the [NHS Data Dictionary](#), procedures can be understood as 'clinical interventions' for the 'for the prevention, cure, relief or diagnosis of disease'. A procedure may be carried out as part of a 'clinical investigation' (a test) where it is both diagnostic and therapeutic, for example, certain endoscopic procedures. Therefore, procedures are primarily used for the treatment or prevention of a problem, and although they can be used for testing and diagnosis, the purpose is primarily therapeutic.

Table 2

Round 1, 2 & 3	Final
<p>A. Is your child? <i>Cross all that apply</i></p> <ul style="list-style-type: none"> • Female • Male • Non-binary • A gender not listed here _____ • Unsure how to describe myself • Prefer not to say <p>B. What sex was your child assigned at birth?</p> <ul style="list-style-type: none"> • Female • Male • Intersex • Prefer not to say 	<p>Q. What best describes your child's gender?</p> <ul style="list-style-type: none"> • Female • Male • A gender not listed here _____ • Prefer not to say

There was low acceptability of the two question approach among parents of 0-7 year olds but the question was trialled again in round two and three to understand the core issues. During cognitive testing some parents/carers felt uncomfortable with being asked about both their child's sex and gender. They felt that in many cases their child was too young to assign their own gender as separate to their sex assigned at birth.

As a result, the parent/carer (0 to 7) questionnaire asks respondents one question (Q49) on their child's gender. The question allows parents/carers the option, using a free text box, to describe the gender which best fits their child, as well as the binary options of 'female' and 'male'. Additionally, an option 'prefer not to say' has been added for the 2020 survey.

8 to 11 Questionnaire

Table 3

Round 1	Round 2	Round 3 & Final
<p>A. Are you? <i>Cross all that apply</i></p> <ul style="list-style-type: none"> • Boy • Girl • Neither • Something else _____ • Unsure • Don't want to say <p>B. What sex were you given at birth?</p> <ul style="list-style-type: none"> • Boy • Girl • Neither • Don't want to say 	<p>Are you? <i>Cross all that apply</i></p> <ul style="list-style-type: none"> • Boy • Girl • Neither • Something else _____ • Unsure • Don't want to say <p>Moved to Parents section</p> <p>B. What sex was your child assigned at birth?</p> <ul style="list-style-type: none"> • Female • Male • Intersex • Prefer not to say 	<p>Child's Questionnaire</p> <p>Q. What best describes your gender?</p> <ul style="list-style-type: none"> • Girl • Boy • Something else _____ • Don't want to say <p>Parents Questionnaire</p> <p>Q. What sex was your child assigned at birth?</p> <ul style="list-style-type: none"> • Female • Male • Intersex • Prefer not to say

Round 1 tested two questions with children aged 8 to 11, one asking gender and the other establishing sex assigned at birth. It was found that 8 to 11 year olds were uncomfortable with, and confused by two questions with little understanding of the differences between sex and gender.

For round 2 the decision was made to split the gender and sex questions, asking the child their gender and asking the parent/carer the child's sex given at birth. Although this version solved the sex and gender confusion, 8 to 11 year olds did not understand the term non-binary and thought that there were too many options in the gender question.

Taking these findings on board, two new questions were added to the children's (8 to 11) questionnaire, one question (Q24) on gender in the children's section, and one question (Q61) on sex in the parent/carer section. The above question was included in round three of cognitive testing, it was well received and understood and included in the final questionnaire.

12 to 15 Questionnaire

Table 4

Round 1 & 2 (+ top-up)	Round 3 (+ top-up)	Final
<p>A. Are you?</p> <p><i>Cross all that apply</i></p> <ul style="list-style-type: none"> • Female • Male • Non-binary • A gender not listed here _____ • Unsure how to describe myself • Prefer not to say <p>B. What sex were you assigned at birth?</p> <ul style="list-style-type: none"> • Female • Male • Intersex • Prefer not to say 	<p>A. Are you?</p> <p><i>Cross all that apply</i></p> <ul style="list-style-type: none"> • Female • Male • Non-binary • A gender not listed here _____ • Unsure how to describe myself • Prefer not to say <p>B. Is your gender the same as the sex they were given at birth?</p> <ul style="list-style-type: none"> • Yes • No • Prefer not to say <p>2nd Test Option</p> <p>C. Please tick this box if your gender is different to your sex assigned at birth? <i>This question is optional, you may not need to answer it.</i> <input type="checkbox"/></p>	<p>Q. What best describes your gender?</p> <ul style="list-style-type: none"> • Female • Male • Non-binary • A gender not listed here _____ • Unsure how to describe myself • Prefer not to say <p>Q. Is your gender the same as the sex you were given at birth?</p> <ul style="list-style-type: none"> • Yes • No • Prefer not to say

The young person's questionnaire contains a question on both sex and gender (Q26 and Q27). Cisgender young people, during cognitive testing, generally had a good understanding of both sex and gender, and how these two could differ. Additionally, there was support for the inclusive nature of the questions.

The gender question remained largely unchanged throughout the three rounds of testing due to familiarity and acceptability of the terms and ease of completion.

The question on sex was changed for round three, following the findings from eight cognitive interviews with young people who identified as transgender, non-binary or were unsure. These young people echoed the stakeholder groups views that some transgender individuals prefer not to have to choose an option which states their gender assigned at birth (i.e. male, female) as they no longer identify in that way. The 'yes', 'no', and 'prefer not to say' response options are preferable as they do not overtly ask the respondent to state their sex assigned at birth.

As a result, in the final round of testing, two versions of the new sex question were shown to respondents. Ten top-up interviews were also conducted with young people of all gender to ensure the question was easily understood and completed among this age group more generally.

Safeguarding

Lastly, the comment section disclaimer at the end of the questionnaire was amended to clarify to whom and in which situation patient comments and/or personal data of the respondent would be provided back to the NHS trusts. The text reads '*Your details will **only** be passed back to the NHS Trust if **your comments in this section** raise concerns for your own or others' safety and wellbeing*' was added.

10. Changes to the Design of Patient Facing Materials

10.1 Redesigned Covering Letters

The covering letters have been redesigned to take account of developments across the wider NPSP. The design used was adopted based on cognitive testing findings and according to best practice principles of design. The changes include:

- Using NHS blue colour to highlight key words and phrases in the letter, reinforcing the recognisability of the NHS.
- Using one of the NHS official fonts (Arial).
- Removing superfluous and repetitive text on the front page.
- Incorporating potentially motivating and empowering messages.

The text on the reverse side of the first and third covering letters has been updated to inform patients how their data will be used and protected as per the requirements of the General Data Protection Regulation (GDPR). The first reminder letter does not have an FAQ section on the reverse side and therefore does not include this text.

Information was added to the covering letter, allowing recipients to request an Easy Read, large print or braille version of the questionnaire. Where available, an email helpdesk address is also included on all cover letters, in addition to the phone helpline.

The first and third mailing letters accompanying questionnaires which parent/carers and children/young people are asked to complete, have been personalised. This personalisation includes the phrasing 'you and your child', rather than just 'you', where appropriate. This is to better indicate that both the child/young person and the parent(s) should complete the questionnaire.

10.2 Multilanguage Sheet

Details for MENCAP were removed from the Multilanguage sheet as MENCAP's services are no longer available. Instead, patients can request accessible versions of the questionnaire (easy read, large print and braille), or an interpreter, from the contractor or in-house trust using the Freephone number provided. Details on how to request an alternative version of the questionnaire are also included on all three covering letters.

11. Changes to the Methodology and Design of Guidance Materials

Two changes have been made to the survey methodology and design this year in order to mitigate the impact of COVID-19. Firstly, an additional sampling month, January 2021, has been added to offset the reduced number of hospital admissions and the subsequent impact on CYP sample sizes. Secondly, additional time has been allowed between mailing of the survey materials to allow for delays in Royal Mail postal delivery.

Three new sample variables were added this year: a mobile phone indicator, a COVID-19 diagnosis variable and a COVID-19 treatment variable. These are detailed below. Additionally, postcode data will be used in analysis for CYP20.

11.1 Sample Period Extension

The most significant change to the survey was the extension of the sampling period by one month, into January 2021. All previous CYP surveys sampled in November and December (trusts with less than 400 eligible patients sampled back to October). Due to the ongoing COVID-19 pandemic and specifically the 'second wave' that hit Britain during the CYP sampling period of November and December 2020, an analysis of admissions data was conducted by CQC to understand the extent of a reduction in hospital admissions and the level of threat this posed to the reliability and value of the CYP 2020 survey. The analysis consisted of:

Analysis 1: Established the extent to which admissions decreased for the survey sampling period and what the likely impact would be on sampling. In mid-November CQC asked a sample of 10 NHS trusts²⁵ and a number of expert stakeholders to provide information on the extent to which children and young people's admissions (up to the age of 15) were down in November 2020 on November 2019. This direct consultation was necessary because of the considerable reporting lags for national data and datasets, such as Hospital Episode Statistics (HES), which mean that 'real-time' or near-real-time admission figures cannot be accessed from central sources.

On average, children and young people's admission were down by around 35% and the analysis concluded that projected drops in admissions across the 2020 survey sampling period were projected to have a considerable impact on sampling for participating trusts. The key findings of the analysis were that a much smaller number of trusts would be able to draw a full sample of 1250

²⁵ Lewisham & Greenwich NHS Trust, University Hospitals of Derby and Burton NHS Foundation Trust, Great Ormond Street Hospital for Children NHS Foundation Trust, Mid Yorkshire Hospitals NHS Trust, Birmingham Women's and Children's NHS Foundation Trust, Manchester University NHS Foundation Trust, Nottingham University Hospitals NHS Trust, Guy's and St Thomas' NHS Foundation Trust, Warrington and Halton Teaching Hospitals NHS Foundation Trust, University Hospitals Bristol and Weston NHS Foundation Trust.

(around 29; down from 68 in 2018) and nearly five times as many trusts would not be able to sample 400 patients – the minimum required – in 2020 (18) than in 2018 (4). This would translate into a drop in national respondent numbers by as much as 8,000.

Analysis 2: Established the likely impact on sampling of extending the sampling period into January 2021.

To establish the likely impact of sampling into January 2021, each trust's reduced population was estimated by reducing the trust's number of admitted children and young people in November and December 2018 (mean = ~2000) by the trust's percentage decline projected for November 2020 (on average, 35%). The population for December was estimated separately and added to the population to model opening the sampling period to January²⁶.

It was projected that opening sampling into January 2021 would largely mitigate drops in admissions across the 2020 survey sampling period. A similar number of trusts to 2018 would be able to draw samples of 1250 patients and a similar number of trusts would struggle to sample 400. The median sample numbers and median respondent numbers were projected to be largely consistent, maintaining the reliability and value of survey data.

Overall it was concluded that sampling into January 2021 would maintain the reliability and value of the survey data, especially for trusts with relatively small numbers of paediatric admissions, and the decision to extend the sampling period was made on this basis.

11.2 Extension to Mailing Timeframe (Faster First Reminder)

During consultation with approved contractors, it was highlighted that due to COVID-19 they are currently experiencing delays in mailing. These delays may impact the CYP20 survey in two ways. Firstly, it may take longer for survey materials to reach potential participants. Secondly, respondent's completed questionnaires may take longer to reach approved contractors for processing.

Currently the faster first reminder system in place means that potential participants will receive a reminder letter (mailing two) five days after receiving their first questionnaire (mailing one). However, due to the current situation, the reminder letters are potentially reaching a respondent while their completed questionnaire posted back to the contractor is still in the delayed postal system. This may lead to unnecessary reminders being sent to participants, causing confusion. As a result, the time period between the first mailing and reminder letter (mailing two) has been extended by two days to seven days. This increased time between mailings hopes to avoid the scenario described above where participants receive unnecessary reminders.

11.3 Additional COVID-19 Variables Sample Guidance

In addition to the guidance provided in the CYP20 survey Sampling Instructions, a separate COVID-19 sampling Q&A document will be made available to assist trusts in providing the new variables required this year. The document will contain a number of common questions raised during sampling for the same new variables in the 2020 Adult Inpatients Survey managed by the Survey Coordination Centre for Mixed Methods based at IPSOS MORI.

²⁶ National data shows that gross children and young people's admissions in January are very similar to December. In January 2020 children's admissions were up 1.2% on December 2019.

11.4 Additional Sample Variables

Patient's Full Postcode for Analysis

For 2020 the sample file will include the patient's full postcode. The decision to collect this variable for use in analysis was made as there is interest in examining whether there is a link between deprivation and children's experiences of hospital care. Full postcodes will allow the mapping of case level postcodes to the Lower Layer Super Output Areas (LSOA) deprivation indices (such as the English Index of Deprivation or Index of Multiple Deprivation).

To comply with data protection and specific Section 251 regulation, the postcode information will be stripped out of the final dataset provided to CQC, leaving only the LSOA variable included. All postcode data will be removed by the SCCEM from the dataset produced during cleaning and analysis.

Mobile Phone Indicator

Over the past few years, there have been a number of methodological pilots undertaken across the wider NPSP looking at ways of increasing response rates and encouraging feedback from those groups that tend to be 'harder to reach'. One way in which this has been done is to look at the use of different ways to invite people to respond to surveys and offering different response modes. As progress is made in this area, it is important to understand what information is available at provider level to make these changes possible.

To support this work, trusts will provide an additional sample variable: a mobile phone indicator. Trusts will be asked to include in their sample data whether they hold a mobile phone number for a child/young person, their parent/carer, do not hold a mobile phone number or cannot attribute a phone number to either a child/young person or their parent/carer (number could belong to either parent/carer or child/young person).

COVID-19 Diagnosis

A new COVID-19 diagnosis variable will be requested for the 2020 survey, with the categorisations detailed below. This variable will allow for the analysis of data to understand the experience of COVID-19 patients and how it may differ from those without a COVID-19 diagnosis.

1= COVID-19 positive confirmed via testing

2= COVID-19 suspected but testing inconclusive

3= COVID-19 testing status unknown

4= COVID-19 negative confirmed via testing

5= COVID-19 not suspected, not tested

Trusts are requested to derive this new sample variable from ICD-10 codes and to submit as part of their sample data in Sampling Workbook 2. Trusts that do not have this information available at the time of sample submission will have the opportunity to submit this variable in an attribution data file directly to the SCCEM at a later date.

COVID-19 Treatment

A second COVID-19 indicator was added to indicate whether a patient was treated in hospital as a COVID-19 case or not. This analysis will allow for the breakdown of results by COVID-19 treatment, and whether or not this affected patient experience. Trusts are asked to obtain this information from local records, with categories listed below.

1= Treated as confirmed or suspected COVID-19

2= Treated as non COVID-19

3= Status unknown

As with the COVID-19 diagnosis variable, the COVID-19 treatment variable may be submitted in Workbook 2 as part of a trusts sample, or alternatively, at a later date in an attribution data file.

Appendices

Appendix 1.0 CYP20 Gender Questions

<p>Option A</p> <p>Q. Are you?</p> <p><i>Cross all that apply</i></p> <ul style="list-style-type: none">• Female• Male• Non-binary• A gender not listed here _____• Unsure how to describe myself• Prefer not to say	<p>Option B</p> <p>Q. What best describes your gender?</p> <p><i>Cross all that apply</i></p> <ul style="list-style-type: none">• Female• Male• A gender not listed here _____• Prefer not to say <p>Q. Is your gender different to that assigned at birth?</p> <ul style="list-style-type: none">• Yes• No• Prefer not to say
<p>Option C</p> <p>Q. Are you?</p> <p><i>Cross all that apply</i></p> <ul style="list-style-type: none">• Female• Male• Non-binary• A gender not listed here _____• Unsure how to describe myself• Prefer not to say <p>Q. What sex were you assigned at birth?</p> <ul style="list-style-type: none">• Female• Male• Intersex• Prefer not to say	<p>Option D</p> <p>Q. Are you?</p> <p><i>Cross all that apply</i></p> <ul style="list-style-type: none">• Female• Male• Non-binary• Agender• Gender diverse• A gender not listed here _____• Unsure how to describe myself• Prefer not to say <p>Q. Is your gender different to that assigned at birth?</p> <ul style="list-style-type: none">• Yes• No• Prefer not to say





Appendix 4.0 Multilanguage sheet

LANGUAGE HELP?

<p>If you have any questions about this survey, or you would like help completing it, please call the FREEPHONE number on ☎..... in order to speak to an interpreter.</p>
<p>إذا كان لديك أي استفسار بخصوص الاستبيان، أو ترغب في المساعدة في ملء الاستبيان المرفق، يرجى الاتصال على خط المساعدة المجاني على الرقم ☎.....، للتحدث مع مترجم باللغة العربية.</p>
<p>আপনার যদি এই সার্ভের বিষয়ে কোন প্রশ্ন থেকে থাকে অথবা আপনি যদি সংশ্লিষ্ট প্রশ্নাবলী পূরণ করবার জন্য কোন সাহায্য চান, তাহলে দয়া করে এই ফ্রিফোন ☎..... হেল্পলাইনে ফোন করুন যেখানে আপনি একজন বাংলা জানা দোভাষী বা ইন্টারপ্রিটারের সাথে কথা বলতে পারবেন।</p>
<p>如果您對此調查有何疑問，或需要協助來完成所附的問卷，請撥打此免費電話 ☎.....，您將會獲得漢語廣東話口譯員的協助。</p>
<p>اگر آپ کے ذہن میں اس سروے کے بارے میں کوئی سوال ہو یا آپ کو اسے پُر کرنے میں مدد کی ضرورت ہو تو براہ مہربانی کسی مترجم سے بات کرنے کے لیے مفت ٹیلی فون نمبر ☎..... پر کال کریں۔</p>
<p>જો તમને આ સર્વેક્ષણ વિશે કોઈ પ્રશ્નો હોય અથવા તે ભરવામાં મદદની જરૂર હોય, તો કૃપાપૂર્વક સાથે વાત કરવા માટે કૃપા કરીને ફ્રીફોન નંબર ☎..... પર ફોન કરો.</p>
<p>আপনার যদি এই সার্ভের বিষয়ে কোন প্রশ্ন থেকে থাকে অথবা আপনি যদি সংশ্লিষ্ট প্রশ্নাবলী পূরণ করবার জন্য কোন সাহায্য চান, তাহলে দয়া করে এই ফ্রিফোন ☎..... হেল্পলাইনে ফোন করুন যেখানে আপনি একজন বাংলা জানা দোভাষী বা ইন্টারপ্রিটারের সাথে কথা বলতে পারবেন।</p>
<p>ئەگەر ھەر پرسپیارێکت ھەبوو دەربارەی ئەم پروژییە یاخود یارمەتیی یۆنیست بوو بۆ پرکردنەوەی ئەم پرۆژەییە کە پاشکۆ کراوە، تکایە تەلەفۆن بکە بۆ ☎..... دەتوانیت ئەمگەڵ مۆتەر جیمیکێ زمانی کوردی سۆزانی قسە بکەیت.</p>
<p>如果您对此调查有何疑问，或需要协助来完成所附的问卷，请拨打此免费电话 ☎.....，您将会获得汉语普通话口译员的协助。</p>
<p>ਜੇਕਰ ਤੁਸੀਂ ਇਸ ਸਰਵੇਖਣ ਬਾਰੇ ਕੋਈ ਸਵਾਲ ਪੁੱਛਣਾ ਚਾਹੋ, ਜਾਂ ਇਸ ਨੂੰ ਭਰਨ ਵਿੱਚ ਮਦਦ ਲੈਣੀ ਚਾਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਫ੍ਰੀਫੋਨ ਨੰਬਰ ☎..... 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ ਜਿਥੇ ਤੁਸੀਂ ਇੱਕ ਦੁਬਾਸ਼ੀ ਦੇ ਨਾਲ ਪੰਜਾਬੀ ਵਿੱਚ ਗੱਲ ਕਰ ਸਕਦੇ ਹੋ।</p>
<p>இந்த ஆய்வு சம்பந்தமாக உங்களிடம் ஏதாவது கேள்விகள் இருப்பின், அல்லது ஆய்வுக்கான வினாக்கொத்ததை நிரப்புவதற்கு உதவி தேவைப்படின, தயவு செய்து ☎..... எனும் இலவச தொலைபேசி இலக்கத்தை அழைக்கவும். இத்தொலைபேசியில் நீங்கள் ஓர் உரை மொழிபெயர்ப்பாளருடன் பேசமுடியும்.</p>

<p>หากท่านมีข้อสงสัยเกี่ยวกับแบบสอบถามนี้ หรือต้องการความช่วยเหลือในการตอบคำถาม กรุณาโทรติดต่อหมายเลขฟรี ☎..... ที่ท่านสามารถคุยกับล่ามภาษาไทยได้</p>
<p>Bu anketle ilgili sorularınız varsa veya ekteki anket formunu doldurmak için yardım almak istiyorsanız, aşağıdaki ücretsiz YARDIM HATTIMIZI arayarak Türkçe konuşan bir tercümanla görüşebilirsiniz. ☎.....</p>
<p>اگر در مورد این زمینه یابی سوالی دارید و یا برای پر کردن آن به کمک احتیاج دارید، لطفاً با شماره تلفن رایگان کمک تماس بگیرید تا بتوانید با مترجم فارسی زبان صحبت کنید.☎</p>
<p>Si vous avez des questions au sujet de cette enquête ou que vous aimeriez recevoir de l'aide pour remplir le questionnaire ci-joint, veuillez appeler le service d'assistance téléphonique GRATUIT au ☎..... afin de pouvoir parler à un interprète français.</p>
<p>Se ha domande su questa indagine oppure necessita di assistenza per la compilazione del questionario allegato, La preghiamo di contattare il numero di assistenza gratuito ☎..... per parlare con un interprete di lingua italiana.</p>
<p>Prosimy zadzwonić pod podany poniżej bezpłatny numer infolinii, aby porozmawiać z tłumaczem w języku polskim i uzyskać odpowiedzi na pytania dotyczące ankiety lub pomoc w wypełnieniu załączonego formularza. ☎.....</p>
<p>Se tiver alguma pergunta sobre este inquérito, ou se precisar de ajuda para o preencher, por favor telefone para a seguinte linha telefónica GRATUITA, onde poderá falar em Português com um intérprete: ☎.....</p>
<p>Если у вас возникнут какие-либо вопросы по поводу настоящего опроса, или вам понадобится помощь в заполнении анкеты, пожалуйста, звоните на БЕСПЛАТНЫЙ НОМЕР ☎....., чтобы поговорить через переводчика.</p>
<p>Haddii aad wax su'aalo ah ka qabtid daraasaddan, ama doonaysid in lagaa caawiyo buuxinta daraasadda, fadlan soo wac lambar TELEEFONKA BILAASHKA ah ee ☎..... si aad ula hadashid turjumaan Soomaali ah.</p>
<p>Si tiene alguna pregunta acerca de este cuestionario o necesita ayuda para rellenarlo, llame al número de teléfono gratuito ☎....., donde podrá hablar con un intérprete español.</p>

LEARNING DIFFICULTY OR REQUIRE AN EASY READ, LARGE PRINT OR BRAILLE QUESTIONNAIRE?

If you have a learning difficulty and you need some help to fill in this survey, or require a copy of the questionnaire in Easy Read, large print or braille, please call our freephone helpline on

Appendix 5.0 Questionnaire mapping

CYP20 0-7 Parent/Carer Questionnaire	CYP20 8-11 Children's Questionnaire	CYP20 12-15 Young People's Questionnaire	Summary of changes
	CYP complete section	CYP complete section	
	THE HOSPITAL WARD	THE HOSPITAL WARD	
	1. Did hospital staff play with you or do any activities with you while you were in hospital?		
		1. Was the ward suitable for someone of your age?	
	2. Were there enough things for you to do in the hospital?	2. Were there enough things for you to do in the hospital?	
	3. If you used the hospital Wi-Fi, was it good enough to do what you wanted?	3. If you used the hospital Wi-Fi, was it good enough to do what you wanted?	
	4. Did you like the hospital food?	4. Did you like the hospital food?	
	5. Was it quiet enough for you to sleep when needed in the hospital?	5. Was it quiet enough for you to sleep when needed in the hospital?	
	LOOKING AFTER YOU IN HOSPITAL	LOOKING AFTER YOU IN HOSPITAL	
	6. Did hospital staff talk with you about how they were going to care for you?	6. Did hospital staff talk with you about how they were going to care for you?	
	7. When the hospital staff spoke with you , did you understand what they said?	7. When the hospital staff spoke with you , did you understand what they said?	
	8. Did you feel able to ask staff questions?	8. Did you feel able to ask staff questions?	
	9. Did the hospital staff answer your questions?	9. Did the hospital staff answer your questions?	

CYP20 0-7 Parent/Carer Questionnaire	CYP20 8-11 Children's Questionnaire	CYP20 12-15 Young People's Questionnaire	Summary of changes
	10. Were you involved in decisions about your care and treatment?	10. Were you involved in decisions about your care and treatment?	
	11. When you spoke to hospital staff, did they listen to what you had to say?	11. When you spoke to hospital staff, did they listen to what you had to say?	New question for 2020
	12. If you had any worries, did a member of staff talk with you about them?	12. If you had any worries, did a member of staff talk with you about them?	
	13. Were you given enough privacy when you were receiving care and treatment?	13. Were you given enough privacy when you were receiving care and treatment?	
		14. If you wanted, were you able to talk to a doctor or nurse without your parent or carer being there?	
	PAIN	PAIN	
	14. If you felt pain while you were at the hospital, do you think staff did everything they could to help you?	15. If you felt pain while you were at the hospital, do you think staff did everything they could to help you?	
	OPERATIONS & PROCEDURES	OPERATIONS & PROCEDURES	
	15. During your time in hospital, did you have any operations or procedures? Please do not include blood tests, scans or x-rays.	16. During your time in hospital, did you have any operations or procedures? Please do not include blood tests, scans or x-rays.	Note added: <i>'Please do not include blood tests, scans or x-rays.'</i>
	16. Before the operations or procedures, did hospital staff explain to you what would be done?	17. Before the operations or procedures, did hospital staff explain to you what would be done?	

CYP20 0-7 Parent/Carer Questionnaire	CYP20 8-11 Children's Questionnaire	CYP20 12-15 Young People's Questionnaire	Summary of changes
	17. Afterwards , did staff explain to you how the operations or procedures had gone ?	18. Afterwards , did staff explain to you how the operations or procedures had gone ?	
	LEAVING HOSPITAL	LEAVING HOSPITAL	
	18. Did a member of staff tell you who to talk to if you were worried about anything when you got home?	19. Did a member of staff tell you who to talk to if you were worried about anything when you got home?	
	19. When you left hospital, did you know what was going to happen next with your care?	20. When you left hospital, did you know what was going to happen next with your care?	
	20. Did a member of staff give you advice on how to look after yourself after you went home?	21. Did a member of staff give you advice on how to look after yourself after you went home?	
	AND FINALLY	AND FINALLY	
	21. Do you feel that the people looking after you were friendly?	22. Do you feel that the people looking after you were friendly?	
	22. Overall, how well do you think you were looked after in hospital?	23. Overall, how well do you think you were looked after in hospital?	
		24. <i>This question might be important for children and young people that frequently visit hospital for ongoing care. You may not need to answer it.</i> If you are moving to adult services, did hospital staff give you enough	New question for 12-15 questionnaire 2020

CYP20 0-7 Parent/Carer Questionnaire	CYP20 8-11 Children's Questionnaire	CYP20 12-15 Young People's Questionnaire	Summary of changes
		information about what will happen?	
	ABOUT YOU	ABOUT YOU	
	23. How old are you today?	25. How old are you today?	
	24. What best describes your gender?	26. What best describes your gender?	Amended gender question
		27. Is your gender the same as the sex you were given at birth?	Amended gender question
Parent/Carer complete section	Parent/Carer complete section	Parent/Carer complete section	
1. Did your child stay overnight during their most recent visit to hospital?	26. Did your child stay overnight during their most recent visit to hospital?	29. Did your child stay overnight during their most recent visit to hospital?	
GOING TO HOSPITAL			
2. Was your child's visit to hospital planned or an emergency?	25. Was your child's visit to hospital planned or an emergency?	28. Was your child's visit to hospital planned or an emergency?	
3. Did the hospital give you a choice of admission dates?			
4. Did the hospital change your child's admission date at all?			
THE HOSPITAL WARD	THE HOSPITAL WARD	THE HOSPITAL WARD	
5. For most of their stay in hospital what type of ward did your child stay on?	27. For most of their stay in hospital what type of ward did your child stay on?	30. For most of their stay in hospital what type of ward did your child stay on?	
6. Did the ward where your child stayed have appropriate equipment or	28. Did the ward where your child stayed have appropriate equipment or	31. Did the ward where your child stayed have appropriate equipment or	

CYP20 0-7 Parent/Carer Questionnaire	CYP20 8-11 Children's Questionnaire	CYP20 12-15 Young People's Questionnaire	Summary of changes
adaptations for your child's physical or medical needs?	adaptations for your child's physical or medical needs?	adaptations for your child's physical or medical needs?	
7. How clean do you think the hospital room or ward was that your child was in?	29. How clean do you think the hospital room or ward was that your child was in?	32. How clean do you think the hospital room or ward was that your child was in?	
8. Was your child given enough privacy when receiving care and treatment?			
9. Were there enough things for your child to do in the hospital?			
10. Did staff play with your child at all while they were in hospital?			
11. If your child used the hospital Wi-Fi to entertain themselves, was it good enough to do what they wanted?			
12. Were you able to be with your child as much as you needed to?	30. Were you able to be with your child as much as you needed to?	33. Were you able to be with your child as much as you needed to?	New question for 2020
HOSPITAL STAFF	HOSPITAL STAFF	HOSPITAL STAFF	
13. Did new members of staff treating your child introduce themselves?			
14. Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	31. Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	34. Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	
15. Did members of staff treating your child communicate with them in			

CYP20 0-7 Parent/Carer Questionnaire	CYP20 8-11 Children's Questionnaire	CYP20 12-15 Young People's Questionnaire	Summary of changes
a way that your child could understand?			
16. Did a member of staff agree a plan for your child's care with you ?	32. Did a member of staff agree a plan for your child's care with you ?	35. Did a member of staff agree a plan for your child's care with you ?	
17. Did you have confidence and trust in the members of staff treating your child?	33. Did you have confidence and trust in the members of staff treating your child?	36. Did you have confidence and trust in the members of staff treating your child?	
18. Did staff involve you in decisions about your child's care and treatment?	34. Did staff involve you in decisions about your child's care and treatment?	37. Did staff involve you in decisions about your child's care and treatment?	
19. Were you given enough information to be involved in decisions about your child's care and treatment?	35. Were you given enough information to be involved in decisions about your child's care and treatment?	38. Were you given enough information to be involved in decisions about your child's care and treatment?	
20. Did hospital staff keep you informed about what was happening whilst your child was in hospital?	36. Did hospital staff keep you informed about what was happening whilst your child was in hospital?	39. Did hospital staff keep you informed about what was happening whilst your child was in hospital?	
21. Were you able to ask staff any questions you had about your child's care?	37. Were you able to ask staff any questions you had about your child's care?	40. Were you able to ask staff any questions you had about your child's care?	
22. Did different staff give you conflicting information?			
23. Were the different members of staff caring for and treating your child aware of their medical history?	38. Were the different members of staff caring for and treating your child aware of their medical history?	41. Were the different members of staff caring for and treating your child aware of their medical history?	
24. Did you feel that staff looking after your child knew how to care for their needs?	39. Did you feel that staff looking after your child knew how to care for their needs?	42. Did you feel that staff looking after your child knew how to care for their needs?	Amended question: 'special or individual' removed from question wording

CYP20 0-7 Parent/Carer Questionnaire	CYP20 8-11 Children's Questionnaire	CYP20 12-15 Young People's Questionnaire	Summary of changes
25. Were members of staff available when your child needed attention?	40. Were members of staff available when your child needed attention?	43. Were members of staff available when your child needed attention?	
26. Did the members of staff caring for your child work well together?	41. Did the members of staff caring for your child work well together?	44. Did the members of staff caring for your child work well together?	
27. If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?	42. If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?	45. If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?	
HOSPITAL FOOD			
28. Did your child like the hospital food provided?			
FACILITIES	FACILITIES	FACILITIES	
29. Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	43. Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	46. Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	
30. Were you able to prepare food in the hospital if you wanted to?	44. Were you able to prepare food in the hospital if you wanted to?	47. Were you able to prepare food in the hospital if you wanted to?	
31. Did you stay overnight with your child during their most recent visit to hospital?	45. Did you stay overnight with your child during their most recent visit to hospital?	48. Did you stay overnight with your child during their most recent visit to hospital?	
32. How would you rate the facilities for parents or carers staying overnight?	46. How would you rate the facilities for parents or carers staying overnight?	49. How would you rate the facilities for parents or carers staying overnight?	
PAIN	PAIN	PAIN	
33. If your child felt pain while they were at the hospital, do you think staff	47. If your child felt pain while they were at the hospital, do you think staff	50. If your child felt pain while they were at the hospital, do you think staff	

CYP20 0-7 Parent/Carer Questionnaire	CYP20 8-11 Children's Questionnaire	CYP20 12-15 Young People's Questionnaire	Summary of changes
did everything they could to help them?	did everything they could to help them?	did everything they could to help them?	
OPERATIONS AND PROCEDURES	OPERATIONS AND PROCEDURES	OPERATIONS AND PROCEDURES	
34. During their stay in hospital, did your child have any operations or procedures ? <i>Please do not include blood tests, scans or x-rays</i>	48. During their stay in hospital, did your child have any operations or procedures ? <i>Please do not include blood tests, scans or x-rays</i>	51. During their stay in hospital, did your child have any operations or procedures ? <i>Please do not include blood tests, scans or x-rays</i>	Note added: <i>'Please do not include blood tests, scans or x-rays.'</i>
35. Before your child had any operations or procedures did a member of staff explain to you what would be done ?	49. Before your child had any operations or procedures did a member of staff explain to you what would be done ?	52. Before your child had any operations or procedures did a member of staff explain to you what would be done ?	
36. Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	50. Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	53. Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	
37. During any operations or procedures, did staff play with your child or do anything to distract them?	51. During any operations or procedures, did staff play with your child or do anything to distract them?	54. During any operations or procedures, did staff play with your child or do anything to distract them?	
38. Afterwards , did staff explain to you how the operations or procedures had gone ?	52. Afterwards , did staff explain to you how the operations or procedures had gone ?	55. Afterwards , did staff explain to you how the operations or procedures had gone ?	
LEAVING HOSPITAL	LEAVING HOSPITAL	LEAVING HOSPITAL	
39. Did a staff member give you advice about caring for your child after you went home?	53. Did a staff member give you advice about caring for your child after you went home?	56. Did a staff member give you advice about caring for your child after you went home?	
40. Did a member of staff tell you who to talk to if you were worried about			

CYP20 0-7 Parent/Carer Questionnaire	CYP20 8-11 Children's Questionnaire	CYP20 12-15 Young People's Questionnaire	Summary of changes
your child when you got home?			
41. When you left hospital, did you know what was going to happen next with your child's care?	54. When you left hospital, did you know what was going to happen next with your child's care?	57. When you left hospital, did you know what was going to happen next with your child's care?	
42. Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	55. Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	58. Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	
OVERALL	OVERALL	OVERALL	
43. Do you feel that the people looking after your child listened to you?			
44. Do you feel that the people looking after your child were friendly?			
45. Do you feel that your child was well looked after by the hospital staff?			
46. Do you feel that you (the parent/carer) were well looked after by hospital staff?	56. Do you feel that you (the parent/carer) were well looked after by hospital staff?	59. Do you feel that you (the parent/carer) were well looked after by hospital staff?	
47. Were you treated with dignity and respect by the people looking after your child?	57. Were you treated with dignity and respect by the people looking after your child?	60. Were you treated with dignity and respect by the people looking after your child?	
48. Overall...(please circle a number)	58. Overall...(please circle a number)	61. Overall...(please circle a number)	
	59. Who was the main person who answered the questions in the children's	62. Who was the main person who answered the questions in the children's	

CYP20 0-7 Parent/Carer Questionnaire	CYP20 8-11 Children's Questionnaire	CYP20 12-15 Young People's Questionnaire	Summary of changes
	section of the questionnaire?	section of the questionnaire?	
ABOUT YOUR CHILD	ABOUT YOUR CHILD	ABOUT YOUR CHILD	
<i>The following questions will help us to understand how experiences vary between different groups of the population.</i>	<i>The following questions will help us to understand how experiences vary between different groups of the population.</i>	<i>The following questions will help us to understand how experiences vary between different groups of the population.</i>	New note for 2020
49. What best describes your child's gender?			Amended 0-7 question for 2020
50. What is your child's year of birth?			
51. Including this visit , how many times has your child been to hospital in the past six months?	60. Including this visit , how many times has your child been to hospital in the past six months?	63. Including this visit , how many times has your child been to hospital in the past six months?	
	61. What sex was your child assigned at birth?		Amended 8-11 question for 2020
55. Which of these best describes your child's ethnic background? (Cross ONE only)	62. Which of these best describes your child's ethnic background? (Cross ONE only)	64. Which of these best describes your child's ethnic background? (Cross ONE only)	
52. Does your child have any physical or mental conditions, disabilities to illnesses that have lasted or are expected to last for 12 months or more?	63. Does your child have any physical or mental conditions, disabilities to illnesses that have lasted or are expected to last for 12 months or more?	65. Does your child have any physical or mental conditions, disabilities to illnesses that have lasted or are expected to last for 12 months or more?	
53. Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)	64. Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)	66. Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)	

CYP20 0-7 Parent/Carer Questionnaire	CYP20 8-11 Children's Questionnaire	CYP20 12-15 Young People's Questionnaire	Summary of changes
54. Do any of these reduce your child's ability to carry out day-to-day activities?	65. Do any of these reduce your child's ability to carry out day-to-day activities?	67. Do any of these reduce your child's ability to carry out day-to-day activities?	

Appendix 6.0 Questionnaire A: 0-7 parents and carers

The following tables provides a summary of changes for the parents/carers (0-7), children's (8-11) and young people's (12-15) questionnaires in comparison with the 2018 Children and Young Peoples Patient Experience questionnaires.

CYP20 0-7 Parent/Carer Questionnaire	Question number 2018	Question number 2020	Comments and notes
Did your child stay overnight during their most recent visit to hospital?	Q1	Q1	
Was your child's visit to hospital planned or an emergency?	Q2	Q2	
Did the hospital give you a choice of admission dates?	Q3	Q3	
Did the hospital change your child's admission date at all?	Q4	Q4	
For most of their stay in hospital, what type of ward did your child stay on?	Q5	Q5	
Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?	Q6	Q6	
How clean do you think the hospital room or ward was that your child was in?	Q7	Q7	
Was your child given enough privacy when receiving care and treatment?	Q8	Q8	
Were there enough things for your child to do in the hospital?	Q9	Q9	
Did staff play with your child at all while they were in hospital?	Q10	Q10	

CYP20 0-7 Parent/Carer Questionnaire	Question number 2018	Question number 2020	Comments and notes
If your child used the hospital Wi-Fi to entertain themselves, was it good enough to do what they wanted?	Q11	Q11	
Were you able to be with your child as much as you needed to?		Q12	New question for 2020
Did new members of staff treating your child introduce themselves?	Q12	Q13	
Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	Q13	Q14	
Did members of staff treating your child communicate with them in a way that your child could understand?	Q14	Q15	
Did a member of staff agree a plan for your child's care with you ?	Q15	Q16	
Did you have confidence and trust in the members of staff treating your child?	Q16	Q17	
Did staff involve you in decisions about your child's care and treatment?	Q17	Q18	
Were you given enough information to be involved in decisions about your child's care and treatment?	Q18	Q19	

CYP20 0-7 Parent/Carer Questionnaire	Question number 2018	Question number 2020	Comments and notes
Did hospital staff keep you informed about what was happening whilst your child was in hospital?	Q19	Q20	
Were you able to ask staff any questions you had about your child's care?	Q20	Q21	
Did different staff give you conflicting information?	Q21	Q22	
Were the different members of staff caring for and treating your child aware of their medical history?	Q22	Q23	
Did you feel that staff looking after your child knew how to care for their needs?	Q23	Q24	Amended question: 'special or individual' removed from question wording
Were members of staff available when your child needed attention?	Q24	Q25	
Did the members of staff caring for your child work well together?	Q25	Q26	
If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?	Q26	Q27	
Did your child like the hospital food provided?	Q27	Q28	
Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	Q28	Q29	
Were you able to prepare food in the hospital if you wanted to?	Q29	Q30	

CYP20 0-7 Parent/Carer Questionnaire	Question number 2018	Question number 2020	Comments and notes
Did you stay overnight in hospital with your child during the most recent visit?	Q30	Q31	
How would you rate the facilities for parents or carers staying overnight?	Q31	Q32	
If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	Q32	Q33	
During their stay in hospital, did your child have any operations or procedures? Please do not include blood tests, scans or x-rays.	Q33	Q34	Note added: 'Please do not include blood tests, scans or x-rays.'
Before your child had any operations or procedures did a member of staff explain to you what would be done?	Q34	Q35	
Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	Q35	Q36	
During any operations or procedures, did staff play with your child or do anything to distract them?	Q36	Q37	
Afterwards , did staff explain to you how the operations or procedures had gone?	Q37	Q38	
Did a staff member give you advice about caring for your child after you went home?	Q38	Q39	

CYP20 0-7 Parent/Carer Questionnaire	Question number 2018	Question number 2020	Comments and notes
Did a member of staff tell you who to talk to if you were worried about your child when you got home?	Q39	Q40	
When you left hospital, did you know what was going to happen next with your child's care?	Q40	Q41	
Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	Q41	Q42	
Do you feel that the people looking after your child listened to you?	Q42	Q43	
Do you feel that the people looking after your child were friendly?	Q43	Q44	
Do you feel that your child was well looked after by the hospital staff?	Q44	Q45	
Do you feel that you (the parent/carer) were well looked after by hospital staff?	Q45	Q46	
Were you treated with dignity and respect by the people looking after your child?	Q46	Q47	
Overall...(please circle a number)	Q47	Q48	
<i>The following questions will help us to understand how experiences vary between different groups of the population.</i>			Note added for 2020

CYP20 0-7 Parent/Carer Questionnaire	Question number 2018	Question number 2020	Comments and notes
What best describes your child's gender?		Q49	Question amended for 2020
Is your child male or female?	Q48		Question amended for 2020
What is your child's year of birth?	Q49	Q50	
Including this visit , how many times has your child been to hospital in the past six months?	Q50	Q51	
Does your child have any physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last for 12 months or more?	Q51	Q52	
Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)	Q52	Q53	
Do any of these reduce your child's ability to carry out day-to-day activities?	Q53	Q54	
Which of these best describes your child's ethnic background? (Cross ONE only)	Q54	Q55	

Appendix 7.0 Questionnaire B: 8-11 Children's

CYP20 8-11 Children's Questionnaire	Question number 2018	Question number 2020	Comments and notes
Did hospital staff play with you or do any activities with you while you were in hospital?	Q1	Q1	
Were there enough things for you to do in the hospital?	Q2	Q2	
If you used the hospital Wi-Fi, was it good enough to do what you wanted?	Q3	Q3	
Did you like the hospital food?	Q4	Q4	
Was it quiet enough for you to sleep when needed in the hospital?	Q5	Q5	
Did hospital staff talk with you about how they were going to care for you?	Q6	Q6	
When the hospital staff spoke with you , did you understand what they said?	Q7	Q7	
Did you feel able to ask staff questions?	Q8	Q8	
Did the hospital staff answer your questions?	Q9	Q9	
Were you involved in decisions about your care and treatment?	Q10	Q10	
When you spoke to hospital staff, did they listen to what you had to say?		Q11	New question for 2020
If you had any worries, did a member of staff talk with you about them?	Q11	Q12	

CYP20 8-11 Children's Questionnaire	Question number 2018	Question number 2020	Comments and notes
Were you given enough privacy when you were receiving care and treatment?	Q12	Q13	
If you felt pain while you were at the hospital, do you think staff did everything they could to help you?	Q13	Q14	
During your time in hospital, did you have any operations or procedures? Please do not include blood tests, scans or x-rays.	Q14	Q15	Note added: <i>'Please do not include blood tests, scans or x-rays.'</i>
Before the operations or procedures, did hospital staff explain to you what would be done ?	Q15	Q16	
Afterwards , did staff explain to you how the operations or procedures had gone ?	Q16	Q17	
Did a member of staff tell you who to talk to if you were worried about anything when you got home?	Q17	Q18	
When you left hospital, did you know what was going to happen next with your care?	Q18	Q19	
Did a member of staff give you advice on how to look after yourself after you went home?	Q19	Q20	
Do you feel that the people looking after you were friendly?	Q20	Q21	
Overall, how well do you think you were looked after in hospital?	Q21	Q22	

CYP20 8-11 Children's Questionnaire	Question number 2018	Question number 2020	Comments and notes
How old are you today?	Q23	Q23	
What best describes your gender?		Q24	Question amended for 2020
Are you a boy or a girl?	Q22		Question amended for 2020
Was your child's visit to hospital planned or an emergency?	Q24	Q25	
Did your child stay overnight during their most recent visit to hospital?	Q25	Q26	
For most of their stay in hospital what type of ward did your child stay on?	Q26	Q27	
Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?	Q27	Q28	
How clean do you think the hospital room or ward was that your child was in?	Q28	Q29	
Were you able to be with your child as much as you needed to?		Q30	New question for 2020
Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	Q29	Q31	
Did a member of staff agree a plan for your child's care with you ?	Q30	Q32	

CYP20 8-11 Children's Questionnaire	Question number 2018	Question number 2020	Comments and notes
Did you have confidence and trust in the members of staff treating your child?	Q31	Q33	
Did staff involve you in decisions about your child's care and treatment?	Q32	Q34	
Were you given enough information to be involved in decisions about your child's care and treatment?	Q33	Q35	
Did hospital staff keep you informed about what was happening whilst your child was in hospital?	Q34	Q36	
Were you able to ask staff any questions you had about your child's care?	Q35	Q37	
Were the different members of staff caring for and treating your child aware of their medical history?	Q36	Q38	
Did you feel that staff looking after your child knew how to care for their needs?	Q37	Q39	Amended question: 'special or individual' removed from question wording
Were members of staff available when your child needed attention?	Q38	Q40	
Did the members of staff caring for your child work well together?	Q39	Q41	
If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?	Q40	Q42	

CYP20 8-11 Children's Questionnaire	Question number 2018	Question number 2020	Comments and notes
Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	Q41	Q43	
Were you able to prepare food in the hospital if you wanted to?	Q42	Q44	
Did you stay overnight in hospital with your child during the most recent visit?	Q43	Q45	
How would you rate the facilities for parents or carers staying overnight?	Q44	Q46	
If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	Q45	Q47	
During their stay in hospital, did your child have any operations or procedures ? Please do not include blood tests, scans or x-rays.	Q46	Q48	Note added: <i>Please do not include blood tests, scans or x-rays.</i>
Before your child had any operations or procedures did a member of staff explain to you what would be done ?	Q47	Q49	
Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	Q48	Q50	
During any operations or procedures, did staff play with your child or do anything to distract them?	Q49	Q51	

CYP20 8-11 Children's Questionnaire	Question number 2018	Question number 2020	Comments and notes
Afterwards , did staff explain to you how the operations or procedures had gone ?	Q50	Q52	
Did a staff member give you advice about caring for your child after you went home?	Q51	Q53	
When you left hospital, did you know what was going to happen next with your child's care?	Q52	Q54	
Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	Q53	Q55	
Do you feel that you (the parent/carer) were well looked after by hospital staff?	Q54	Q56	
Were you treated with dignity and respect by the people looking after your child?	Q55	Q57	
Overall...(please circle a number)	Q56	Q58	
Who was the main person who answered the questions in the children's section of the questionnaire?	Q57	Q59	
<i>The following questions will help us to understand how experiences vary between different groups of the population.</i>			Note added for 2020
Including this visit , how many times has your child been to hospital in the past six months?	Q58	Q60	

CYP20 8-11 Children's Questionnaire	Question number 2018	Question number 2020	Comments and notes
What sex was your child assigned at birth?		Q61	Question amended and added to parent/carer section for 2020
Which of these best describes your child's ethnic background? (Cross ONE only)	Q59	Q62	
Does your child have any physical or mental conditions, disabilities to illnesses that have lasted or are expected to last for 12 months or more?	Q60	Q63	
Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)	Q61	Q64	
Do any of these reduce your child's ability to carry out day-to-day activities?	Q62	Q65	

Appendix 8.0 Questionnaire C: 12-15 Young People's

CYP20 12-15 Young People's Questionnaire	Question number 2018	Question number 2020	Comments and notes
Was the ward suitable for someone of your age?	Q1	Q1	
Were there enough things for you to do in the hospital?	Q2	Q2	
If you used the hospital Wi-Fi, was it good enough to do what you wanted?	Q3	Q3	
Did you like the hospital food?	Q4	Q4	
Was it quiet enough for you to sleep when needed in the hospital?	Q5	Q5	
Did hospital staff talk with you about how they were going to care for you?	Q6	Q6	
When the hospital staff spoke with you , did you understand what they said?	Q7	Q7	
Did you feel able to ask staff questions?	Q8	Q8	
Did the hospital staff answer your questions?	Q9	Q9	
Were you involved in decisions about your care and treatment?	Q10	Q10	
When you spoke to hospital staff, did they listen to what you had to say?		Q11	New question for 2020
If you had any worries, did a member of staff talk with you about them?	Q11	Q12	

CYP20 12-15 Young People's Questionnaire	Question number 2018	Question number 2020	Comments and notes
Were you given enough privacy when you were receiving care and treatment?	Q12	Q13	
If you wanted, were you able to talk to a doctor or nurse without your parent or carer being there?	Q13	Q14	
If you felt pain while you were at the hospital, do you think staff did everything they could to help you?	Q14	Q15	
During your time in hospital, did you have any operations or procedures? Please do not include blood tests, scans or x-rays.	Q15	Q16	Note added: 'Please do not include blood tests, scans or x-rays.'
Before the operations or procedures, did hospital staff explain to you what would be done?	Q16	Q17	
Afterwards , did staff explain to you how the operations or procedures had gone?	Q17	Q18	
Did a member of staff tell you who to talk to if you were worried about anything when you got home?	Q18	Q19	
When you left hospital, did you know what was going to happen next with your care?	Q19	Q20	
Did a member of staff give you advice on how to look after yourself after you went home?	Q20	Q21	
Do you feel that the people looking after you were friendly?	Q21	Q22	

CYP20 12-15 Young People's Questionnaire	Question number 2018	Question number 2020	Comments and notes
Overall, how well do you think you were looked after in hospital?	Q22	Q23	
<p><i>This question might be important for children and young people that frequently visit hospital for ongoing care.</i></p> <p>You may not need to answer it. If you are moving to adult services, did hospital staff give you enough information about what will happen?</p>		Q24	New question and note for 2020
How old are you today?	Q24	Q25	
What best describes your gender?		Q26	Question amended for 2020
Is your gender the same as the sex you were given at birth?		Q27	Question amended for 2020
Are you male or female?	Q23		Question amended for 2020
Was your child's visit to hospital planned or an emergency?	Q25	Q28	
Did your child stay overnight during their most recent visit to hospital?	Q26	Q29	
For most of their stay in hospital what type of ward did your child stay on?	Q27	Q30	
Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?	Q28	Q31	

CYP20 12-15 Young People's Questionnaire	Question number 2018	Question number 2020	Comments and notes
How clean do you think the hospital room or ward was that your child was in?	Q29	Q32	
Were you able to be with your child as much as you needed to?		Q33	New question for 2020
Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	Q30	Q34	
Did a member of staff agree a plan for your child's care with you ?	Q31	Q35	
Did you have confidence and trust in the members of staff treating your child?	Q32	Q36	
Did staff involve you in decisions about your child's care and treatment?	Q33	Q37	
Were you given enough information to be involved in decisions about your child's care and treatment?	Q34	Q38	
Did hospital staff keep you informed about what was happening whilst your child was in hospital?	Q35	Q39	
Were you able to ask staff any questions you had about your child's care?	Q36	Q40	

CYP20 12-15 Young People's Questionnaire	Question number 2018	Question number 2020	Comments and notes
Were the different members of staff caring for and treating your child aware of their medical history?	Q37	Q41	
Did you feel that staff looking after your child knew how to care for their needs?	Q38	Q42	Amended question: 'special or individual' removed from question wording
Were members of staff available when your child needed attention?	Q39	Q43	
Did the members of staff caring for your child work well together?	Q40	Q44	
If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?	Q41	Q45	
Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	Q42	Q46	
Were you able to prepare food in the hospital if you wanted to?	Q43	Q47	
Did you stay overnight in hospital with your child during the most recent visit?	Q44	Q48	
How would you rate the facilities for parents or carers staying overnight?	Q45	Q49	
If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	Q46	Q50	

CYP20 12-15 Young People's Questionnaire	Question number 2018	Question number 2020	Comments and notes
During their stay in hospital, did your child have any operations or procedures? Please do not include blood tests, scans or x-rays.	Q47	Q51	Note added: <i>'Please do not include blood tests, scans or x-rays.'</i>
Before your child had any operations or procedures did a member of staff explain to you what would be done?	Q48	Q52	
Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	Q49	Q53	
During any operations or procedures, did staff play with your child or do anything to distract them?	Q50	Q54	
Afterwards , did staff explain to you how the operations or procedures had gone?	Q51	Q55	
Did a staff member give you advice about caring for your child after you went home?	Q52	Q56	
When you left hospital, did you know what was going to happen next with your child's care?	Q53	Q57	
Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	Q54	Q58	
Do you feel that you (the parent/carer) were well looked after by hospital staff?	Q55	Q59	

CYP20 12-15 Young People's Questionnaire	Question number 2018	Question number 2020	Comments and notes
Were you treated with dignity and respect by the people looking after your child?	Q56	Q60	
Overall...(please circle a number)	Q57	Q61	
Who was the main person who answered the questions in the children's section of the questionnaire?	Q58	Q62	
<i>The following questions will help us to understand how experiences vary between different groups of the population.</i>			Note added for 2020
Including this visit , how many times has your child been to hospital in the past six months?	Q59	Q63	
Which of these best describes your child's ethnic background? (Cross ONE only)	Q60	Q64	
Does your child have any physical or mental conditions, disabilities to illnesses that have lasted or are expected to last for 12 months or more?	Q61	Q65	
Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)	Q62	Q66	
Do any of these reduce your child's ability to carry out day-to-day activities?	Q63	Q67	