**NHS Patient Survey Programme**

# 2018 Children and Young People's Patient Experience Survey:
Quality and Methodology Report

# Contents

# Introduction

The 2018 Children and Young People's Patient Experience Survey (CYP18) is the third iteration in a series of surveys focusing on patient experiences of children and young people, and was conducted as part of the NHS Patient Survey Programme (NPSP). The CYP survey was first undertaken in 2014, again in 2016 and 2018. The survey captures the experiences of children and young people aged 8 to 15 years and the parents and carers of children and young people aged 0 to 15 years. Data were collected to understand children and young people's experiences of NHS acute hospital care in 2018 and used to generate information to facilitate targeted quality improvement.

The 2018 iteration of the survey involved 129 acute and specialist NHS trusts. In total, 33,179 completed questionnaires were received; a response rate of 25%. Three survey versions were created for different age groups:

- The 0-7 questionnaire; sent to parents/carers of patients aged between 15 days and 7 years old at the time of discharge.

- The 8-11 questionnaire; sent to parents/carers of patients aged between 8 and 11 years old at the time of discharge.

- The 12-15 questionnaire; sent to parents/carers of patients aged between 12 and 15 years old at the time of discharge.

Questionnaires sent to those aged 8-11 and 12-15 had a short section for the child or young person to complete, followed by a separate section for their parent or carer to complete. Where a child was aged 0-7, the questionnaire was completed entirely by their parent or carer.

Information drawn from surveys in the NPSP are used by the Care Quality Commission (CQC) in its assessment of trusts in England. The results of the surveys are also used by NHS England and NHS Improvement, and the Department of Health and Social Care to understand patient experience and highlight areas for improvement.

This report details the quality and methodological issues relating to CYP18. It covers the development, implementation, data quality, and analysis of the survey, as well as the quality of the data and any points that should be noted when using the outputs. Additional information on the development of the 2018 survey and errors made during the sampling process can also be found on the NHS surveys website.

The survey is coordinated by the Survey Coordination Centre for Existing Methods (SCCEM), based at Picker. The SCCEM has worked with CQC to develop each of the questionnaires for the 2018 Children and Young People's Patient Experience Survey.

An overview of the approaches taken to ensure quality within the NHS Patient Survey Programme (NPSP) is available in the NHS Patient Survey Programme: Quality Statement.

# Survey Development

## Survey Design and Implementation

The NPSP is committed to best practice for all stages of the survey, including the processes taken to improve the methodology. From extensive desk research, consultation with stakeholders and pilot work across the NPSP, a number of measures have been implemented to help maximise response rates, including:

- The development of survey questions that are relevant to all, or most, people in the sample.

- Questionnaires are written using clear and simple language.

- Use of cognitive interviewing to test questions and response options with people who have recently used NHS services, in order to ensure that they are easily understood and relevant.

- Reassurances of anonymity and confidentiality are made.

- Up to two reminders are sent to non-responders.

There is a long fieldwork period to encourage less frequently heard demographic groups, such as minority ethnic groups, to respond[1].

- The availability of a Freephone language line that provides translation services.

- MENCAP provided support for people with learning difficulties to complete the questionnaire.

- Use of a Quality Assurance Framework ensuring all survey materials and results are reliable and accurate.

Like most surveys in the NPSP, the Children and Young People's Patient Experience Survey uses a postal survey approach, with a questionnaire being sent to the residential address of potential participants. This method enables a probability sample to be drawn as it reduces any selection bias that may be present if the survey was administered by front line staff at the time of their hospital visit when, for example, busy staff may not have the time to distribute questionnaires to all patients, or may not give questionnaires to patients who they do not think will give favourable feedback. It also removes the possibility of a social desirability bias occurring, which may happen when people give feedback either directly to staff or whilst on hospital premises, where respondents are more likely to give positive responses during face-to-face interviews.

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[1] For more information please see:
http://www.nhssurveys.org/Filestore/documents/Extension_of_fieldwork_for_inpatient_survey_2007.pdf

A number of steps are taken to ensure the robustness of the survey design and implementation. As with all surveys in the NPSP, an external advisory group was formed to ensure a range of stakeholders were given the opportunity to provide input during survey development.

There is further information in the Questionnaire Development section about the people interviewed during the development of the 2018 questionnaire.

There were five main methodological changes to the survey in 2018:

- The dissent poster was translated and made available in the ten most commonly spoken languages in England.

- The time between the first and second mailing was shortened from 2-3 weeks to five working days. This followed a pilot study on the adult inpatient survey (2017) which found a significant increase in response rate with a faster first reminder (40.8% to 44%).

- The survey's name changed from the 'Children and Young People's Inpatient and Day Case Survey' (2016 survey) to the 'Children and Young People's Patient Experience Survey' (2018 survey). This name change was a result of the survey's sampling approach also including 'ordinary admissions' as classified by the NHS Data Dictionary[2].

- The illustrations used throughout the 8-11 and 12-15 year olds questionnaires were updated in the 2018 survey. Recent children and young people's research into quality of care[3] identified that imagery used to engage with this population should not directly relate to illness or a hospital setting but depict children and young people outside of the hospital setting. The images commissioned for the 2018 survey were also updated to be as inclusive and reflective of this diverse population as possible. The information leaflet for this survey was also updated with the revised illustrations (see appendices).

- The covering letters were updated to include the use of colour for key words and phrases, written with a more informal tone alongside the inclusion of socio normative messaging (e.g. "Thousands of people across England have already responded") and the removal of superfluous and repetitive text. The FAQ's on the letters were also updated to reflect the requirements of the General Data Protection Regulation (GDPR). These changes were made as a result of a methodological pilot on the 2017

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[2] Historically, the sampling criteria for this survey was defined as 'inpatient' or 'day case' according to the NHS Data Dictionary. However, there are another group of patients according to the NHS Data Dictionary who are classed as 'ordinary admissions' who are eligible for the survey. The name of the survey was consequently changed to reflect that some patients may not be inpatient or day case, but an ordinary admission.

[3] Wray, Hobden, Knibbs, and Oldham (2018) "Hearing the voices of children and young people to develop and test a patient-reported experience measure in a specialist paediatric setting".

community mental health survey which saw a 4 percentage point increase in overall response rate as a result of similar changes to the covering letters for that population.

Further information about methodological changes can be found in the Survey Development Report.

The Children and Young People's Patient Experience Survey follows a strict methodology, as specified in the Survey Handbook, which all in-house trusts[4] and approved contractors[5] must follow. Any deviation from the survey instructions, depending on severity, may result in data being excluded from published results. Any decision to exclude data is made by the Survey Team at CQC in conjunction with the SCCEM, based on discussion with, and evidence provided by, the trust(s). No trusts were excluded from the 2018 Children and Young People's Patient Experience Survey publication.

# Questionnaire Development

To ensure that the questionnaire is up-to-date and in line with current policy and practice, questions are reviewed before each survey to determine whether any new questions are needed. These changes, and the reasons for them, are detailed in the survey development report, available on the NHS Surveys website.

All three versions of the questionnaire were revised for the 2018 survey. The changes were made to ensure the survey continues to provide the most useful and relevant feedback possible, addressing both the issues of importance to patients and generating information of significance for policy evaluation and the regulation of NHS trusts. Amendments were made on the basis of the following considerations:

- Analysis of the 2016 survey data to examine item non-response rates, as well as floor and ceiling effects.

- Consultation with stakeholders, including CQC, Picker Institute, NHS England and NHS Improvement, as well as the CQC Children's Survey Advisory Group, which comprises representatives from the Department of Health and Social Care, UCL Great Ormond Street Institute of Child Health, several NHS Trusts (Royal Brompton & Harefield NHS foundation trust, North Devon Healthcare NHS Trust and Great Ormond Street Hospital), CLIC Sargent, a member of the NHS Youth Forum and a CQC expert by experience.

- Cognitive interviews were conducted with 36 participants split across three rounds, to ensure that the question wording and response options in each survey version were both suitable and understandable to respondents.

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[4] These are trusts which have opted to carry out the survey themselves. In 2018 one trust conducted the survey in-house.
[5] These are companies which have been approved by the CQC during a competitive tendering process to carry out NPSP survey on behalf of trusts. For more information see here.

Alterations made to the questionnaire for the 2018 survey fall into three categories; new questions, removed questions, and amended questions. In 2016, there were 76 questions: in the 2018 survey, there were 79 questions. Eight new questions were added to the 2018 questionnaire (one new question for CYP, and 7 for parents/carers), 4 were removed (all were parent/ carer questions) and 5 were amended. The section title for 'Facilities for parents & carers' was changed to 'Facilities' in all three questionnaire versions.

Cognitive interviews were carried out in Oxfordshire, Berkshire, Bristol and London with a total of 19 parents/carers interviewed:

- 6 were the parent/carer of a child aged 0-7

- 7 were the parent/carer of a child aged 8-11

- 6 were the parent/carer of a young person aged 12-15

- 14 of these were the parent/carer of a female, and 5 were the parent/carer of a male

- 8 were the parent/carer of a child/young person from black and minority ethnic groups.

- 11 were the parent/carer of a child/young person with a long term condition

A total of 17 children and young people were interviewed:

- 9 of these were children aged 8-11

- 8 of these were young people aged 12-15

- 8 were male, and 9 were female

- 5 participants were from black and minority ethnic groups.

- 8 participants had long-term conditions.

For more information about the cognitive testing process and amendments made to the 2018 survey, please see the Survey Development Report.

# Sampling and Fieldwork

## Sampling

One hundred and twenty nine trusts took part in the 2018 Children and Young People's Patient Experience Survey. Patients were eligible to participate in the survey if they were admitted to hospital and aged between 15 days and 15 years old when discharged between the 1st of November and the 31st December 2018. Five trusts were unable to achieve the required sample size in November and December (1250 patients), and so sampled from October to December to reach their maximum sample size.

Trusts were instructed that their sample should exclude:

- Patients who were not admitted (e.g. ward attendees or patients who attended an outpatient appointment, but were not admitted)
- Deceased patients
- Any duplicated patients
- Patients aged 16 years or older at the time of their discharge
- Babies aged between 0 and 14 days at the time of their discharge
- New-born babies where the mother was the primary patient (i.e. well babies, treatment function code 424)
- Patients who were only admitted to a Neonatal Intensive Care Unit (NICU) or a Special Care Baby Unit (SCBU) (Treatment Function Code 422)
- Obstetrics/maternity patients, including spontaneous miscarriages
- Patients admitted for planned termination of pregnancy
- Psychiatry patients, including CAMHS
- Private patients (non-NHS)
- NHS patients treated at private hospitals
- Any patients who are known to be current inpatients
- Patients without a UK postal address
- Please note: patients were included if they had an address in any part of the UK, including those not in England (Wales, Scotland, Northern Ireland, Isle of Man, Channel Islands, etc.). Equally, patients whose address was at a military base, care home or prison establishment were also eligible.
- Any patient, parents or carers known to have requested that their details were not used for any purpose other than their clinical care. (This does not include patients who opted out of having their data used for planning and research purposes via the National Data Opt-Out Programme.)

Fieldwork for the survey (the time during which questionnaires were sent out and returned) took place between 11th February and 14th June 2019.

The length of time in field was dependent on the time it took trusts to submit a correct sample to the Survey Coordination Centre for Existing Methods for approval. Very few trusts were able to take advantage of the full fieldwork period. Due to sampling issues, 8 trusts did not begin fieldwork until April and May. These trusts were only in field for between 9 weeks and 5 days and 4 weeks and 5 days.

Bespoke analysis was conducted to determine whether the short fieldwork period had impacted response rates or respondent demographics. Analysis revealed that the main threat to data integrity was that the pattern of response by patient demographic groups differed from the pattern that would be expected given the maximum opportunity to respond, i.e. that there is additional non-response bias arising from the time in field. Additionally, two trusts showed significant departures from the expected pattern of response by service type (medical or surgical cases). Benchmark and outlier analysis were standardised using route of admission (elective/emergency), length of stay (0 nights stay/1 or more night's stay) and

age group (0-7/8-11/12-15). These weights help to mitigate the bias caused by late entry to fieldwork.

# Sampling Methodology

As in the 2016 survey, a disproportionate systematic, stratified sampling method was used for the 2018 Children and Young People's Patient Experience Survey with a total sample size of 1250 patients. The original approach of a consecutive discharge (non-stratified) method, as adopted in the 2014 iteration of the survey, resulted in a higher proportion of 0-7s being sampled (i.e. a higher proportion of the total sample) compared with 8-15 year olds. This resulted in very little useable data for 8-15 year olds due to the low sample sizes in each sub group. The disproportionate stratification approach allows a fixed sample size (i.e.: quota) to be sampled from each age group enabling trusts to increase the number of patients aged 8-15 years old within their sample compared to what they would most likely achieve if a proportionate sampling method was adopted. It effectively allows the 8-11 and 12-15 year old age groups to be 'oversampled' compared to the number of hospital admissions. In 2014, despite there being more sampled patients in the 0-7 category, the response rate for this age group was actually lower than the 8-11 and 12-15 year old age groups. Again, by adopting a disproportionate sampling approach and setting a fixed quota, we can prepare for the expected lower response rate.

In practice, this meant the following steps were taken: first, a list of all eligible patients discharged during November and December 2018 was compiled; in cases where a patient had been admitted more than once during the sampling period, the most recent attendance was retained. Second, this list was sorted sequentially, first by gender, then year of birth, and finally by month of birth. The third step involved drawing the sample from the ordered list of patients. In doing this, CYP18 adopted a systematic multi-stage stratified selection approach. Basic multi-stage sampling is a more complicated version of cluster sampling, where the total population is divided into clusters, or groups, and individuals are selected at random from these clusters. However, the multi-stage stratified sampling method used here differs from this, in that after dividing the population by the first-level clusters, the resulting sub-clusters are further sub-divided in accordance with some selection criteria. The key point of the approach adopted for CYP18 is that, at every consecutive sub-division, the sample size becomes smaller and more precise.

For CYP18, this involved each trust dividing its total eligible population into clusters in accordance with the three distinct survey groups, each of which targeted a specific age group: 0-7 years, ($A1$), 8-11 years of age, ($A2$), and 12-15 years of age, ($A3$). Each trust attempted to submit a total sample of 1,250 patients, broken down into the three age groups as follows: $A1$ = 450 patients $A2$ = 400 patients $A3$ = 400 patients. The sampling interval is the crucial component of the CYP18 methodology, and is what constitutes the stratified component of the approach. The sampling interval refers to the way in which one in every $k$ record is sampled as they become available; where $k$ is the rounded quotient of dividing the total population size, $p$, by the total sample size, $s$: $k = \left\lfloor \frac{p}{y} \right\rfloor$.

# Sampling Error

As the survey does not use a random sample, sampling error calculations were not applicable when determining the minimum sample size. The maximum sample size for CYP18 was 1,250 participants per trust; of which there are 129.

This sample size was large enough to minimise sampling error; a much smaller sample size could have resulted in a trust sampling a subset of patients who could have had a significantly more positive or negative experience than their population as a whole. Assuming the sample period is not atypical, then given the large sample size and number of responses, the 2018 sample can be considered representative of the target population.

The final data had a total of 33,179 responses, resulting in a response rate of 25.09%. The size of the final data sample was large enough when data from all age groups were aggregated that its sampling error was very small. This patient data can therefore be insightful when looked at for England as a whole (i.e. the data for all trusts pooled) with a focus on the questions that were answered by all participants.

# Trust mergers

Since the last iteration of the CYP survey in 2016, there have been six trust mergers with implications for the survey. Birmingham Women's Foundation Trust and Birmingham Children's Foundation Trust merged to form Birmingham Women's and Children's NHS Foundation Trust. As service provision and population served did not change as a result of this merger, historical comparisons could have been provided. However, as detailed below, a historic sampling error meant this trust did not receive historic comparisons in 2018.

Due to service provision changes following mergers or acquisitions, historical comparisons were not provided for Manchester University NHS Foundation Trust, East Suffolk and North Essex NHS Foundation Trust, North West Anglia NHS Foundation Trust, University Hospitals Birmingham and University Hospitals of Derby and Burton.

# Errors in drawing samples

The chances of mistakes being made by trusts when drawing their sample are minimised by multi-stage sample checks. In the first instance, trusts are provided with a checklist to review their drawn sample. Those trusts that appoint an 'approved contractor'[6] to undertake the survey on their behalf will have their sample reviewed by this company.

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[6] These are companies approved by the Care Quality Commission during a competitive tendering process to carry out surveys in the NHS Patient Survey Programme on behalf of trusts. For more information please see: www.nhssurveys.org/approvedcontractors

All anonymised samples are then checked by the SCCEM, who look for errors that are more noticeable when pooling data together; for example, unusual or skewed age distributions. Items are also checked against the trust's data submissions for previous iterations of the survey, to help ascertain whether or not the trust has followed the sampling instructions correctly. These checks include comparisons of population size, demographics, etc. Should there be any discrepancies that merit investigation, queries will be raised with the trust or contractor responsible for the data sample.

Any errors identified during this process are categorised as either minor or major in nature. The former is defined as a mistake that will not affect the usage or quality of the survey response data. An example of this is if the patient record numbers (PRN's) are applied in an incorrect format. This is an error that could be rectified by the trust, contractor or the SCCEM by amending the sample's PRNs, which would not undermine the quality of the sample.

A major error is defined as a mistake that would affect the usage or quality of the survey response data. An example of this is an error in extract coding which leads to a biased sample, such as a disproportionate number of males to females. This error would result in a trust having to re-draw the sample in line with the guidance.

A sampling errors report, which details the errors identified by the Survey Coordination Centre for Existing methods, is produced after each iteration of the survey. There were 4 major errors and 1 minor error in the 2018 iteration of the survey.

The 'Statement of Administrative Sources' outlines the chances of errors occurring at the stage where trusts input patient data into administrative systems; data from which samples are drawn.[7] It was concluded that, although the potential does exist for inaccurate addresses or coding of cases at this stage, this is unlikely to occur due to the data quality requirements placed upon NHS trusts. As a result, the chances of such errors occurring at this stage are small enough that any impact upon trust results are likely to be minimal, and in turn, would have an even smaller effect upon the aggregated results for England.

Additionally, the sample declaration form is used to help further reduce sampling errors. This form not only outlines a number of checks that have to be completed, but also ensures adherence to the sampling methodology on the part of both the sampler and the trust's Caldicott Guardian. Crucially, this form also ensures that trusts have maintained confidentiality of patients by taking the steps laid out in the instruction manual, such as only passing on specific variables. Approval of this form prior to data submission thus fulfils the trust's own requirements under the Data Protection Act, as well as reducing the potential for breaches to the support received under Section 251 of the NHS Act 2006[8].

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[7] https://www.cqc.org.uk/sites/default/files/20170210_surveys_statement_of_administrative_sources.pdf

[8] Section 251 of the NHS Act 2006 provides a legal basis for the transfer of data to a survey contractor.

## Historical Sampling Errors and excluded trusts

The sample checking process carried out by the SCCEM involves comparing trust sample data to that from previous iterations of the survey, to help ensure that the sample has been drawn correctly. For CYP18, sample data was compared to that submitted for the 2016 survey. On occasion, these checks can find errors made during these previous survey iterations. These are important to note as, if any of these errors are deemed to be major ones, then historical comparisons may not be an option for the trust in question.

As a result of these historical checks, four trusts were excluded from being provided historical comparisons to 2016:

- Royal Surrey County Hospital NHS Foundation Trust
- Dartford and Gravesham NHS Trust
- Birmingham Women's and Children's NHS Foundation Trust

For more information about the historical errors identified during the 2018 survey please see the Sampling Errors Report.

# Fieldwork

Fieldwork for the 2018 Children and Young People's Patient Experience Survey took place between February and June 2019. Each week during fieldwork, approved contractors and in-house trusts sent a weekly monitoring report to the SCCEM, summarising the survey's outcome status with the following codes:

- Outcome 1 = questionnaire returned completed

- Outcome 2 = questionnaire returned undelivered

- Outcome 3 = service user deceased after fieldwork commenced

- Outcome 4 = service user too ill, opted out or returned blank questionnaire

- Outcome 5 = service user ineligible

- Outcome 6 = questionnaire not returned

- Outcome 7 = service user deceased prior to fieldwork.

From the above outcome codes, adjusted response rates were calculated each week by dividing service users who returned a completed questionnaire (Outcome 1) by all service users who potentially received the questionnaire and were potentially able to respond:

$$Adjusted\ response\ rate = \frac{outcome\ 1}{\sum(outcome\ 1, 4, 5\ and\ 6)}$$

Weekly monitoring allowed the SCCEM to track the progress of the survey throughout fieldwork and identify and assist with any problems that arose.

# Data Analysis and Reporting

## Data Cleaning and Editing

Survey data from each participating trust are submitted for cleaning to the SCCEM. During fieldwork, a data cleaning guidance manual covering the checks that the SCCEM undertakes is made available, to allow participating trusts and contractors to understand the data cleaning processes and the types of common errors.

The data are submitted to the SCCEM using an Excel spreadsheet. However, the final dataset for the survey is in a SPSS data file format. A version of this data is available for secondary data users at the UK Data Service (UKDS).

There are a number of standard checks that are undertaken on the data, including:

- Checks of the hard copies of questionnaires from contractors and trusts to verify that questions, response options, routing, and instructions are as they should be.[9]

- Check the number of rows of data is as expected, i.e. the correct number of patients are in the data file.

- Variable, question, and response option wording checks; ensuring that the data matches the questionnaire.

- Out of range checks for variables such as age, on both sample and response data.

- Incorrect filtering, where respondents have answered a question that does not apply to them.

- Coding errors whereby the answer given is outside the expected range of response options for a given question.

- Data validation, whereby the response data is used to confirm whether the sample data submitted by the trust is valid for certain demographics.

- Use of the response data to check that only eligible patients were included in the survey.

The data are also checked for other errors. This includes exploring questionnaire item non-response, to check whether there are high levels of missing data on suites of questions positioned next to each other on survey pages. This may indicate an issue with page turnover, as well as whether a question is being understood as intended.

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[9] The SCCEM has since implemented a further check in which a subset of scanned questionnaires are checked during fieldwork to ensure no changes were made after the hard copies were signed off.

All quantitative response data will be supressed so that questions with fewer than 20 valid (specific) responses per trust will be recoded to '996' i.e. cleaned responses. The procedure of data suppression is implemented across the NPSP to protect against respondents potentially being identified and because the confidence interval around the trust's question score is considered too large to be meaningful. Demographic and proxy response question items (response data) are excluded from suppression, in line with other surveys on the national program. The threshold applied to the CYP survey is unique to this survey only: for the rest of the surveys within the NPSP, the threshold is set at < 30 responses. Adopting a lower threshold for the CYP survey specifically enables more data to be reported whilst maintaining confidentiality and anonymity requirements.

Scored variables have been suppressed where there are fewer than 30 responses for a question. These are then cross-referenced against the raw data submitted by the trust to ensure that the suppression process was applied correctly.

# Question Amendments

Please also note that question X63: "During your time in hospital, did you have any operations or procedures?", a routing question for two children and young people's questions on operations and procedures, did not feature the example "such as having your tonsils taken out" in 2018. Cognitive testing for the 2018 survey revealed that the example biased children's responses as they were likely to fail to report they had an operation or procedure because they didn't specifically have their tonsils taken out. Nationally, a larger proportion of children reported an operation or procedure this year (+5%) than in 2016. Whilst a larger proportion of children and young people reported having an operation or procedure, the overall 'yes' response to this question has decreased by 3% (when looked at nationally) with fewer parents saying that their child / young person had an operation or procedure. This decrease was predominantly driven by the parents of 0-7 year olds where the decline in 'yes' was 5% (there was in fact a 2% *increase* in 'yes' for parents of 8-11 year olds). Historical comparisons have been maintained at trust level and nationally.

# Changes to 2016 outputs

Retrospective cleaning was applied to the 2016 data for X28, "Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)" (X25 in 2016). This was to align the 2016 cleaning approach with the one undertaken for 2018. Thus, the figures presented for 2016 data in the national tables output in 2018 may differ slightly to the data in the 2016 publication. The cleaned data for X25 in 2016 were included in the 2018 benchmark data and reports, and benchmark data for 2016 has been reissued.

During data checks of the 2018 national tables it was discovered that the adjusted trust weights (the weight applied to the national tables analysis) were capped at a maximum of 5.0 in 2016, while for CYP18 the adjusted trust weights were uncapped as per the NPSP wide approach for this analysis. This capping of the weights resulted in small discrepancies between the 2016 published national tables for a number of questions, and the reported 2016 historical data within the 2018 output (typically, to two or three decimal places). It was

agreed that these weights should be uncapped, with the 2016 data being re-run without the cap in place.

# Statistical Release

A statistical release is published, which provides full England-level results for 2018 compared with 2016[10], as well as within year comparison between age groups, where possible, and a multi-level analysis of results for subgroups of patients. In order to control for the influence of individual trusts' response rates on the England-level average, data are standardised[11].

The multi-level analysis of subgroups highlights the experiences of different demographic subgroups. Results for each demographic subgroup are generated as adjusted means (also known as estimated marginal means or population marginal means) using a linear mixed effects model. These means are compared on patient-centred care themes, derived from composites of results from specific questions.

To assess whether experiences differ by demographic factors, F tests were performed on each factor (fixed effect) as a predictor of the target variable. P-values are also generated to show the likelihood of differences between groups observed in the results arising from a population where no actual differences occur. They relate to the demographic factor as a whole rather than to comparisons between specific categories within the factor. Variables are also checked for multicollinearity to ensure co-efficient estimates are not influenced by additional factors.

Differences of at least 0.1 standard deviations from the overall mean of the target variable are treated as being noteworthy if the confidence intervals do not cross the mean line.

For CYP18, the following demographic factors were analysed:

- Age group

- Gender

- Ethnicity

- Disability or long-term condition

- Medical/Surgical episode

- Length of stay

- Number of hospital stays in past six months

- Type of ward (children's ward, adolescent/teenage ward, adult ward)

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[10] Comparisons are done using a Z-test of column proportions with the design effect calculated.
[11] More information on the standardisation approach applied to the data can be found in Section 6.5 'Addressing non-response bias in the survey results.

One additional factor was analysed for version B (age 8-11) and C (age 12-15) of the questionnaire:

- Main person who answered the questions in the children's/young people's section of the questionnaire.

The themes of person-centred care against which these sub-groups were compared are as follows:

Parents/ carers:

- Involvement (welcoming the involvement of family and friends): X15, X17, X20

- Preferences (individual preferences and needs): X6, X23

- Confidence: X16

- Medical history: X22

- Dignity: X46

- Concerns: X26

- Overall question: X45


Children and young people:

- Information (information, communication and education): X54, X55, X57

- Transition (transition and continuity): X67, X68

- Respect (respect for patient centred values, preferences and expressed needs): X58, X60

- Food: X52

- Activities: X50
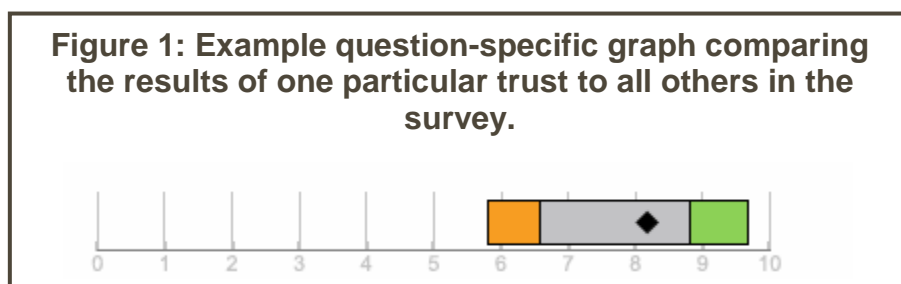
- Worries: X59

- Overall question: X70

# Trust Results

Analysis is conducted on the data at trust level, so as to allow comparisons to be drawn between the performance of different trusts for individual questions in the survey. A report is produced for each individual trust, which illustrates how the trust performed on each question when compared to all other trusts. The method for this analysis is detailed in the technical document. The results of this analysis are published in benchmark reports and made available on the CQC's website.

For evaluative questions, each response option is assigned a score (0-10). Demographic questions, non-specific responses, some routing questions and questions that do not evaluate a trust's performance are not scored. A trust's question score is calculated by taking the weighted average of responses for the trust, for the given question.

A chart is then produced for every scored question and each section of the questionnaire, unless a question has fewer than 30 responses[12]. Each chart depicts the range of scores for all trusts for its corresponding question/section. An example of such a graph can be seen in Figure 1.

Here, the black diamond indicates the trust's score. If the diamond lies in the orange section, then the trust performed 'worse' than expected when compared to most other trusts.



**Figure 1: Example question-specific graph comparing the results of one particular trust to all others in the survey.**

Similarly, if it lies in the green section, then the trust performed 'better' than most others. If the diamond lies in the grey section, as in the example below, then the trust performed about the same as the other trusts on the question being considered.

The benchmark reports contain two tables. The first details the score for the trust, the lowest and highest trust scores in England for the question, the individual trust score for the question, and the 2016 scores for that trust if historic comparisons are available. The second table details the number of respondents (from the trust and overall), response rate, and demographic information for the trust compared to that of all trusts featured in the survey as a whole[13].

# Quality Assurance

## Approved Contractor/In-House Trust Checks

Each contractor and in-house trust undertake a series of checks at key stages of the survey, especially in the sample preparation and data submission stages, where checks tend to focus on issues such as including ineligible patients. Due to contractors receiving mailing

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[12] If a question has fewer than 30 responses for a given trust, the confidence interval around the trust's question score is considered too large to be meaningful and results are not reported.
[13] 'National' figures are calculated using survey data from all trusts - these figures refer to the sampled population, which may have different characteristics to the population of England.

information, they also do validation checks to see if the address is complete enough for a questionnaire to be sent out. Contractors and in-house trusts will also have internal quality assurance guidelines they follow during the survey.

# SCCEM checks

The first QA checks are on the sample files submitted by either contractors or in-house trusts. These checks help to determine whether there are any errors in the sample file, such as the exclusion of eligible patients.

The SCCEM also check hard copies of the covering letters and questionnaires used by each trust within the survey, with the aim of identifying where errors have been introduced when the survey documents are reproduced by either contractors or in house trusts; errors tend to be typographical in nature.

During the fieldwork stage, the SCCEM monitor the progress of the mailings and response rates at both overall and trust level. While not technically a QA check, this monitoring does allow the SCCEM to flag any concerns regarding how the survey is progressing. This may highlight issues that could have an impact upon the data collected due to low response rates affecting the representativeness of the data, thereby limiting its usability. Furthermore, the survey is administered in a standardised manner, with a set number of mailings during fieldwork and a particular final mailing date, so as to allow younger and black and ethnic minority groups more time to respond, as previous research has shown that these groups take longer to respond. For more information, please see the Survey Handbook.

The final set of QA checks undertaken by the SCCEM focuses on the response data and data analysis. In addition to the checks undertaken on the survey data (see section on data cleaning and editing, above), each stage of the data cleaning process is second- and third-checked internally.

Finally, all analysis outputs, including the trust-level results and England-level reporting, go through a two-stage quality assurance process; being checked by both the SCCEM and CQC. The SCCEM has a three-level quality assurance process for every output that ensures any errors are picked up. This usually requires the output being recreated and checked to ensure the figures are correct. Additionally, any syntax that is used to create an output is checked by a Senior Research Associate, as well as either the Chief Statistician, the Head of Survey Coordination, or the Chief Research Officer, to ensure that the methodology is being correctly carried out.

# Data Limitations

## Context

As with any piece of social research, statistical analysis of the data collected as part of CYP18 is susceptible to various types of errors from different sources. As a result of this, potential sources of error aim to be carefully controlled through development work, in terms of questionnaire design and sampling strategy, which in turn is supported by quality assurance at every stage.

## Seasonal Effects

Participating NHS Trusts selected eligible admitted patients discharged from the trust between 1st November 2018 and 31st December 2018, who were aged between 15 days and 15 years (inclusive) at the time of their discharge. There were 5 trusts who did not manage to draw a 1,250 sample throughout November and December, in this case these trusts were permitted to sample back to October 1st.

Whilst we anticipate that there may be seasonal effects on responses, in the form of factors such as differing staffing levels and school holidays, which may have an impact on patient experience, comparability of the results or their use on assessing the performance of trusts would not be affected given that the sampling period for all trusts participating in the survey is consistent.

## Response Rates

The national response rate for the survey has dropped by just over 1% since it was first launched in 2014. Reduction in response rates is consistent with other surveys in the NHS Patient Survey Programme and social and market research more generally.

Figure 2 illustrates response rate trends for the established surveys in the NHS Patient Survey Programme. The figure shows a clear general downwards trend across all surveys. However, for the 2018 iterations of the Adult Inpatient, Community Mental Health and Urgent and Emergency Care surveys response rates are higher than in 2017 (an increase of 4, 2 and 2 percentage points, respectively).

**Figure 2: Response rates for established surveys in the NHS Patient Survey Programme.**
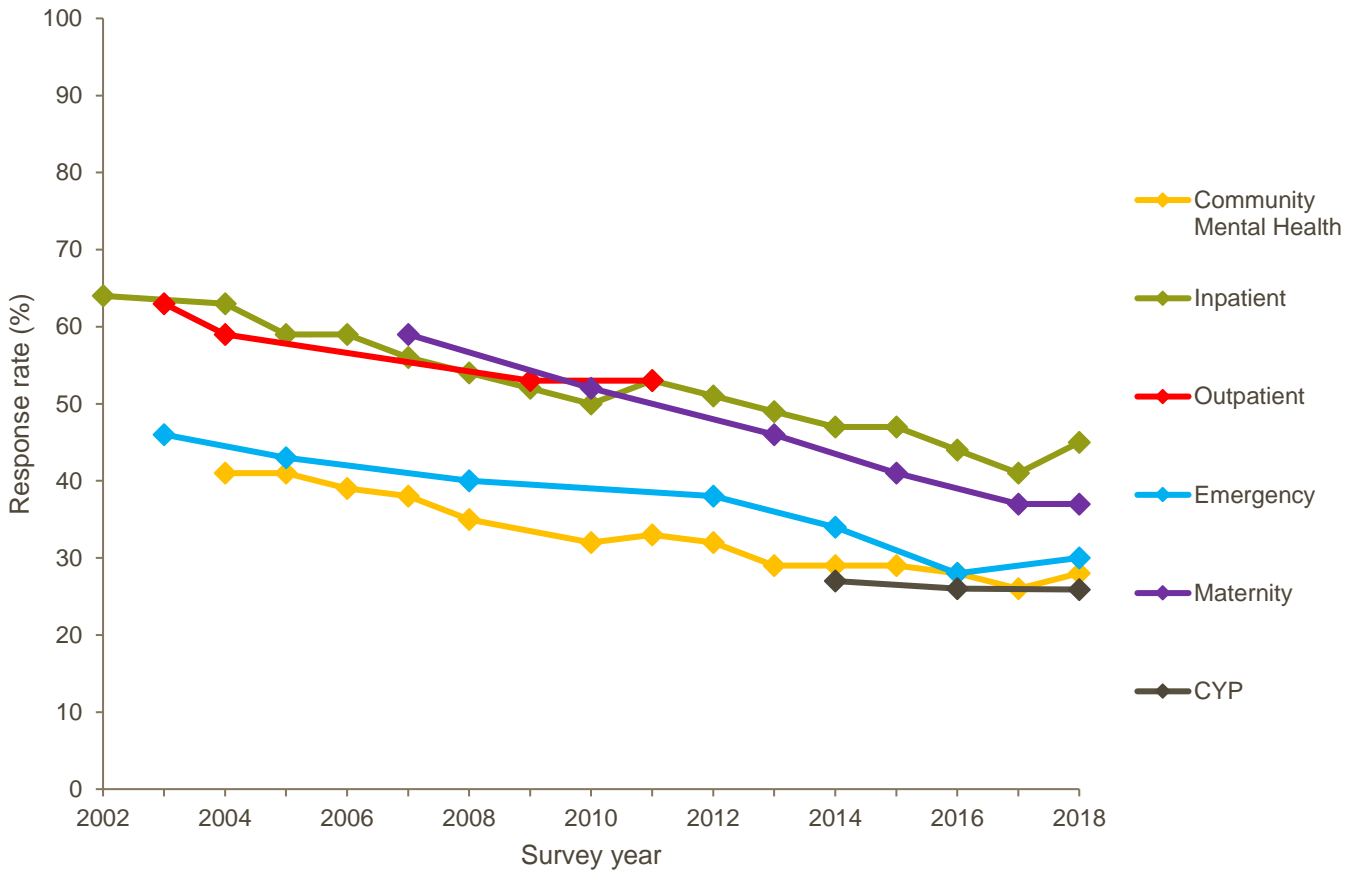


*Please note that not all surveys are conducted on an annual basis.*

# Non-response Bias

One of the main issues that can affect survey results is non-response bias, and as response rates for surveys decline, the risk of non-response bias increases. Non-response bias refers to the outcome that those who chose to respond to the survey are different from those who do not respond. This type of bias would arise, for example, if service users with more positive views of their care were to be more likely to respond than those with negative views. However, whether non-response bias is present is difficult to assess, as we do not have any way of knowing how people who did not respond would have answered.

A further issue is that we cannot always differentiate between those who did not receive a questionnaire and hence could not respond (non-contact) versus those who received a questionnaire but chose not to respond (non-response).

The number of questionnaires that are returned undelivered is logged during the course of the survey. However, there may be another group of service users who, for example,

changed address but did not inform the trust, and therefore did not
receive a questionnaire. It is not possible to know how large this group is.

Furthermore, patient confidentiality prevents the SCCEM from assessing the data quality of the samples that were drawn, as they do not have access to the name and address details of those in the sample population.

Research, carried out as part of the NPSP, has shown that certain groups are consistently less likely to respond, including young people, black and minority ethnic groups (BME), people from deprived areas, those with a mental health condition or poor literacy[14] [15] [16]

It can be seen from tables 1 and 2 below, that there is a non-response bias for this survey, with the parents of children aged 0 to 7 in particular less likely to respond. Table 1 shows the demographic profile for respondents and for the sample as a whole (everyone selected for inclusion in the survey) while table 2 shows demographic information for responders and non-responders. Table 1 shows that older age groups are more likely to respond compared with other age groups, and to a lesser extent, patients who identify as white are more likely to respond than those from other ethnic groups. When interpreting this tables please bear in mind that it is likely that there are also inter-relationships between these groups.

Please note that tables 1 and 2 are based on information from trust sample data[17] only, and will therefore differ from response rates published elsewhere; which are a combination of responses to the demographic questions, or sample file information if the response is missing. Respondent-provided information cannot be used to calculate response rates, as the corresponding information is unavailable for non-responders. The response rate is based on the adjusted response, which means that deceased patients and anyone for whom the questionnaire was undeliverable were removed from the sample.

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[14] www.nhssurveys.org/Filestore/documents/Increasing_response_rates_literature_review.pdf
[15] www.nhssurveys.org/Filestore/documents/Review_BMEcoverage_HCC_surveys.pdf
[16] www.nhssurveys.org/Filestore/documents/Increasing_response_rates_stakeholder_consultation_v6.pdf
[17] Trust sample files contain all people selected to take part in the survey and includes information such as age, gender and ethnicity.

**Table 1: Sample and respondent profiles for the 2018 Children and Young People's Patient Experience Survey.**

| Demographics | Sample | Respondent |
|---|---|---|
| **Gender** | | |
| Male | 55% | 56% |
| Female | 45% | 44% |
| **Age Group** | | |
| 0-7 year olds | 64% | 59% |
| 8-11 year olds | 17% | 19% |
| 12-15 year olds | 19% | 21% |
| **Ethnic Group** | | |
| White | 70% | 69% |
| Multiple ethnic group | 4% | 3% |
| Asian or Asian British | 9% | 8% |
| Black or Black British | 4% | 4% |
| Other ethnic group | 3% | 3% |
| Not stated or any other ethnic group | 12% | 13% |
| **Overnight stay** | | |
| No overnight stay | 60% | 59% |
| Overnight stay | 40% | 41% |

Please note that, due to rounding, the figures in this table may not always sum to 100%.

**Table 2: Respondent and non-respondent profiles for the 2018 Children and Young People's Patient Experience Survey.**

| Demographics | Did not respond including opted out or ineligible | Responded |
|---|---|---|
| **Gender** | | |
| Male | 75% | 25% |
| Female | 75% | 25% |
| **Age Group** | | |
| 0-7 year olds | 77% | 23% |
| 8-11 year olds | 72% | 28% |
| 12-15 year olds | 72% | 28% |
| **Ethnic Group** | | |
| White | 75% | 25% |
| Multiple ethnic group | 78% | 22% |
| Asian or Asian British | 76% | 24% |
| Black or Black British | 75% | 25% |
| Other ethnic group | 72% | 28% |
| Not stated or not known | 72% | 28% |
| **Overnight stay** | | |
| No overnight stay | 75% | 25% |
| Overnight stay | 75% | 25% |

Please note that, due to rounding, the figures in this table may not always sum to 100%.

# Addressing Non-Response Bias in the Survey Results

Non-response weighting is currently applied to the England-level data, but not the trust-level data. In the consideration of whether to weight for non-response and whether this should be in accordance with either the sample or population data, we need to factor in the primary aim of why the survey data are being collected.

For the majority of social research studies, in particular those that are concerned with a cross sectional or general population, non-response is weighted for against the population demographics. This is normally achieved by weighting for key characteristics such as age, gender, marital status, socio-economic status, and if these variables exist either on the sampling frame or are collected at the time of interview. For example, in face-to-face survey interviewing, interviewers are able to collect observations about non-responding sample units by assessing the characteristics of the dwelling or neighbourhood[18]. Alternatively, if a national dataset exists for these key characteristics, such as the Census, then this can be used in deriving the weighting approach. The reason why weighting back to the population is key for these studies is that they are looking to make generalisations about a population as a whole rather than individual cases or sampling units within it.

## Trust-level benchmark analysis

For the NPSP, the data collected are used for measuring and comparing the performance of individual NHS trusts. Therefore, it is important that we are able to distinguish between the characteristics of different trusts (i.e. the variation between them) to identify those trusts that are doing better or worse than the 'average' trust. As demographic characteristics, such as age, gender, route of admission and length of stay are known to be related to responses, we therefore standardise different organisations to a common average case-mix when calculating organisational results. This removes demographic differences as a source of variation and provides a 'level playing field' for comparing providers. Weighting for non-response to either a national population dataset or back to the sample data for a trust would not achieve this.

The potential non-response bias is partly addressed via statistical standardisation by age and sex in the trust level results[19]. Standardising by ethnicity would in theory help address this non-response, however the ability to do this is hindered by a number of limitations detailed below.

Where the response rates for different groups vary, we have considered whether we could additionally weight by groups that are less likely to respond. However, there are a number of drawbacks to this approach, which is why it has not been implemented:

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[18] Lynn, P. (1996) 'Weighting for Non-response' in Banks, R., Fairgrieve, J., Gerrard, L., Orchard, T., Payne, C., & Westlake, A. (eds.) *Survey and Statistical Computing: Proceedings of the Second ASC International Conference*, pg. 205-214, Essex, UK: Association for Survey Computing.
[19] For more information on the methodology for the trust level results, please see the technical document which is referenced in 'Further Information' at the end of this document.

- As more variables are included in the standardisation, the analysis not only becomes more complex, but it also greatly increases the risk of very small groups with large weights.

- In order to weight data by age, gender and ethnicity, and include this in the trust data, information on each of these variables is required. If a respondent has not answered the corresponding questions that provide this information, then it is acquired from the sample file provided by the trust in a bid to maximise the amount of available data. However, while data for age and gender tends to be of very good quality, ethnicity is often quite poor. The survey analysis relies solely on respondent-provided information for ethnicity and, as a result, standardisation by ethnicity would often result in the removal of records from the analysis. This is not desirable, particularly in a survey already suffering from low response rates.

- Due to some trusts having very low proportions of individuals from particular ethnic groups, weights are capped[20] so as to avoid heavy weighting; which should be avoided as far as possible when standardising data as it limits the comparisons that can be made fairly.

Furthermore, it should be noted that direct assessment of non-response bias upon survey data is difficult to measure due to the ethical implications of acquiring such data. This would require further contact with patients who do not wish to be contacted. A future possibility would be to collect additional sampling variables, such as postcode data, that could be linked to non-response. Rather than further adjusting the data, this issue is managed by adopting best-practice methodologies so as to maximise response rates from all groups, as discussed in the [Survey Design and Implementation](#) section.

## Results for England

Some trusts have a higher response rate than others and would therefore have a greater influence over the England average if a simple mean was calculated across all respondents. To avoid this, 'trust' weights were applied to the data. Doing so means that each trust has an equal influence over the England average for each question, regardless of differences in response rates between trusts.

Additional 'population' weights were also introduced in the 2016 survey, with the aim of reducing potential non-response bias by accommodating differential age response rates as well as the stratified survey design that provides for a fixed sample size in each age band. The aim here was to weight the results for each individual trust to the trust's eligible population profile, with the intention of making each trust's results representative of their own population.

Assuming that responses were missing at random, then weighting each trust's results to their eligible population in this way theoretically makes the trust's results more representative of their population, thus potentially yielding a more accurate experience of the average trust.

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[20] To prevent the possibility of excessive weight being given to respondents in an extremely underrepresented group, the maximum value for any weight was set at five.

However, it is not possible to check the extent to which this 'missing at random' assumption is satisfied as there is a lack of data on the reasons behind non-response.

The introduction of non-response weights to the England-level results in a 'design effect' that reduces the precision of statistics from the survey. This has been taken into account for year-to-year comparisons. The design effect can be estimated as the following, where $w_i$ is the weight for respondent $i$ and $n_{total}$ is the total number of respondents:

$$DEFF = \frac{n_{total} * \left[\sum_i w_i^2\right]}{[\sum_i w_i]^2}$$

This is then used to adjust the alpha value for the tests of column proportions in national tables for England, using alpha_new = 2-tailed probability for a result at least as extreme as $|1.95996398454 \times \sqrt{DEFF}|$. The purpose of the adjustment is to maintain the true test value at alpha = 0.05 (the standard applied through the survey programme) in the face of the variance inflation due to the weighting. Given that both within year and between year comparisons were made, two separate design effects were calculated: 1.12877687189556 for year to year comparisons (i.e. 2016 to 2018) and 1.1379734329493 for within year comparisons (i.e. age group comparisons within 2018).

In order to compare within year results between age groups, a z-test was carried out on the data to determine whether there were any statistically significant differences between data from the 0-7, 8-11 and 12-15 versions of the questionnaire ($p < 0.05$). A statistically significant difference means it is very unlikely we would have obtained this result by chance alone if there was no real difference.

This weighting has been applied to the England-level results for all except the demographic questions. These questions are presented without weights applied, as it is more appropriate to present unadjusted data that describes the demographic profile of respondents, rather than average figures.

# Data Revisions

CQC publishes a [Revisions and Corrections Policy](#) relating to these statistics. The NPSP data are not subject to any scheduled revision due to the surveys capturing the views of patients about their experiences of care at a specific point in time. All new survey results are therefore published on the CQC website and NHS Surveys website, as appropriate, and published results for previous iterations of the survey are not revised. The Revisions and Corrections Policy sets out how CQC will respond if an error is identified within this and it becomes necessary to correct published data and/or reports.

# Further Information

The England and trust level results for the 2018 survey are available on the CQC website.
https://www.cqc.org.uk/childrenssurvey

Benchmark reports for each trust are available on the NHS surveys website:
https://nhssurveys.org/all-files/01-children-patient-experience/05-benchmarks-reports/2018/

The results for the 2016 and 2014 survey can be found at the link below. However, please note that due to redevelopment work carried out ahead of the 2016 survey, **results from 2018 are only comparable with 2016.**
https://nhssurveys.org/surveys/survey/01-children-patient-experience/year/2016/

Full details of the methodology for the survey, including questionnaires, letters sent to patients, instructions on how to carry out the survey and the survey development report, are available at:
http://nhssurveys.org/surveys/survey/01-children-patient-experience/year/2018/

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

More information about how CQC monitors hospitals is available on the CQC website at:
www.cqc.org.uk/content/monitoring-nhs-acute-hospitals

# Feedback

We welcome all feedback on the survey findings and the approach we have used to report the results, particularly from people using services, their representatives, and those providing services. If you have any views, comments or suggestions on how this publication could be improved, please contact Tamatha Webster, Surveys Manager, at Patient.Survey@cqc.org.uk.

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

# Appendices

**Figure 3.**

**Figure 4.**