

# CHILDREN AND YOUNG PEOPLE'S PATIENT EXPERIENCE SURVEY 2018

## SURVEY HANDBOOK

Last updated: 12 December 2018

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## Did you know?

- Throughout this document there are hyperlinks to detailed information on the topics covered.
- If you are reading this on your computer, clicking on any of the blue underlined text will give you more information and/or take you directly to the document you need. You will need to press the 'Ctrl' button on your keyboard as you click on the link.
- Generic information and instructions that apply to all surveys in the programme can be found on our NHS Surveys website here:  
<http://www.nhssurveys.org/usefullinks>.
- For detailed instructions and templates that are specific to the 2018 Children and Young People's Patient Experience Survey, please go to:  
<http://nhssurveys.org/surveys/1234>

## Patient feedback and the NHS Constitution

Improving the experience of each individual patient is at the centre of the NHS Constitution. Obtaining [feedback from patients](#) and taking account of their views and priorities are vital for the delivery of high quality services and for driving real service improvements.

The NHS Constitution requires that NHS services reflect the needs and preferences of patients, their families and their carers. It is therefore important that all NHS trusts carry out local surveys asking patients their views on the care they have received. It is intended that measuring patients' experiences in a structured way will act as an incentive to make patient experience a real and central priority for the NHS. The NHS Patient Survey Programme (NPSP) is an important mechanism for making the NHS more patient-focused and provides a quantifiable way of achieving this by:

- Providing information to support local quality improvement initiatives
- Tracking changes in patient experience locally over time
- Providing information for active performance management
- Providing information to support public and parliamentary accountability
- Providing information for the Care Quality Commission's programme of reviews and inspections.

## The Care Quality Commission (CQC)

The NHS Patient Survey Programme (NPSP) was established by the Department of Health and Social Care (DHSC) and has been operating since 2002. CQC is the independent regulator of health and adult social care in England. CQC regulates care provided by the NHS, private companies and voluntary organisations, and aims to ensure that better care is provided for everyone.

The Survey Coordination Centre for the NPSP, of which this survey is part, is based at [Picker](#) and works under contract to CQC to design, test, and coordinate the surveys in this programme. Please note that the Survey Coordination Centre is a completely separate division at Picker from the approved contractor. A [full list of CQC-approved contractors can be found on the NPSP website](#).

### CQC monitoring

Information drawn from the questions in the 2018 Children and Young People's Patient Experience Survey will be used by CQC in its [assessment of services provided to children and young people](#) in England. Questions from the survey will be used within CQC's performance monitoring tools and within CQC's inspections of services provided to children and young people.

## Meaningful comparisons

CQC will publish comparable data from the survey to allow trusts to make meaningful comparisons between themselves and other trusts based on reliable data. Asking each trust to carry out the 2018 Children and Young People's Patient Experience Survey in a consistent way builds a detailed picture of patients' and their families experiences in each trust. Information collected across England in a consistent way is also essential to support public and parliamentary accountability.

CQC intends to archive the survey data with the UK Data Service after the analysis is completed and published. This will be done with appropriate safeguards that ensure patient confidentiality.

## Setting up a project team

We recommend you [set up a survey team](#) in your trust to assist you. The best way to ensure that your survey is a success is to involve from the beginning those people who have the most impact on patients' experiences and who will be responsible for responding to the results of the survey. As a minimum, you will need a survey lead, a person from your data team who will draw your patient sample and your Caldicott Guardian, who will sign off the sample before the data leaves your trust's systems.

## What's new for 2018?

### Changes to the questionnaire – questions added, modified and removed

All three versions of the questionnaire have been revised for the 2018 survey. Amendments have been made on the basis of the following considerations:

- Consultation with stakeholders, including CQC and NHS England, as well as the 2018 Children and Young People's Patient Experience Survey Advisory Group, which comprises of representatives from the Department of Health and Social Care, several NHS Trusts, NHS Youth Forum, CLIC Sargent (the cancer charity for children and young people) and patient-representatives.
- Analysis of the 2016 survey data to examine item non-response rates and floor / ceiling effects.
- Feedback obtained from children, young people and parents/carers with whom the questionnaires were cognitively tested to ensure that the question wording and response options are both suitable and understandable to respondents.

A survey development report will be published on the NHS Surveys website detailing all the changes that have been made and the specific reasons for these changes. This report will be published by December 2018 and will be available here: <http://nhssurveys.org/surveys/1239>

### Change in survey title

From this year, the name of the survey will change from the 'Children and Young People's Inpatient and Day Case Survey' to the '2018 Children and Young People's Patient Experience Survey'. The new name more accurately reflects the eligible population sampled and the subject of the survey. To avoid confusion, this title will be used in all published documents and communications for the survey moving forward.

### Changes to the covering letters

Covering letters have been revised to reflect the colour format and tone of the letters successfully used in the 2017 Community Mental Health [pilot](#). In addition to the wording and formatting changes, it is now a requirement to print the first reminder letters with a trust letterhead and signatory to match the first and third mailing letters. Apart from the sections highlighted in yellow—which will contain different information for each trust—no other changes to the covering letters should be made. If you have any queries, please contact the [Survey Coordination Centre](#).

### Faster postal reminders

For the 2018 survey, the time between the initial contact (first mailing letter) and first reminder (second mailing letter) will be reduced: the latter will be sent out five working days after the initial mailing.

This decision was made following the results of the 2017 Pilot Study that ran alongside the 2017 NHS Adult Inpatient Survey. A faster postal reminder significantly increased response rates from 41% to 44%.

## Historical comparisons to the 2016 survey

The sampling methodology for the survey has remained unchanged since the last iteration of the survey. As a result, it is expected that reporting for this year's survey will include England and trust-level statistical comparisons with the results of the 2016 Children and Young People's Survey.

## Submitting PDFs and hard copies (for contractors and in-house trusts only)

Before you start printing your questionnaires and covering letters, we strongly recommend you email them as **PDFs** to the Survey Coordination Centre for checking.

In addition, we will still require you to post to us two hard copies of the questionnaires and covering letters **no later than the 18<sup>th</sup> January 2018** to allow time for adjustments to be made if necessary. **Please DO NOT proceed with mailings until you have received approval from the Survey Coordination Centre.**

The hard copies you send to us must be printed **exactly** as those that will be sent out to patients in the sample (e.g. do not print in monochrome as questionnaires and covering letters are required to be sent out **in colour**). Please also remember that you must **not include names and/or addresses** of patients in your sample versions when you send hard copies to us.

The [questionnaires and covering letters](#) should be made publicly available by December 2018, subject to Section 251 and ethics approvals.

## Reformatted instruction manuals

Following development in collaboration with trusts and contractors for the 2017 Adult Inpatient Survey, survey instructions have been redesigned in favour of a [Survey Handbook and Sampling Instruction](#) document. Adopting this format reduces the amount of repetition and makes sections of interest easier to reference. If you have any additional feedback, please contact the [Survey Coordination Centre](#).

## Sample declaration form changes

Some enhancements have been made to the [Sample Declaration Form](#). Free-text comment boxes have been added to allow trusts to explain their entries against checklist items. A larger text box has also been added to allow trusts to explain any expected differences in their sample profile versus previous submissions. These changes are aimed at reducing queries regarding the sample data and thereby getting trusts into fieldwork earlier.

## Important survey-specific information

### Three-questionnaire survey design

The 2018 Children and Young People's Patient Experience Survey uses three different questionnaires, each one appropriate for a different age group of patients sampled:

- **Survey version 'A':** The '0-7 questionnaire'; sent to the parents of patients aged between 15 days and 7 years old at the time of discharge.
- **Survey version 'B':** The '8-11 questionnaire'; sent to patients aged between 8 and 11 years old at the time of discharge.
- **Survey version 'C'** The '12-15 questionnaire'; sent to patients aged between 12 and 15 years old at the time of discharge.

Survey version 'B' and 'C' questionnaires have a short section for the child or young person to complete, followed by a separate section for their parent/carer to complete. The survey version 'A' questionnaire is completed entirely by the sample patient's parent/carer.

When the sample is drawn using the [sample construction workbooks](#), patients sampled for the survey will automatically be assigned to receive one of these questionnaires.

**It is vitally important the correct survey is sent. Data collected via an incorrect questionnaire will likely be excluded. If you are in any doubt, please contact the [Survey Coordination Centre](#).**

### Disproportionate systematic, stratified sampling method

As introduced for the last iteration of the survey, a disproportionate systematic, stratified sampling method will again be used for the 2018 Children and Young People's Patient Experience Survey. This more complex sampling method is intended to ensure that adequate data is received from older patients by 'over-sampling' 8-11 and 12-15 year olds. Without this sampling method, children and young people aged 8-15 would account for a problematically small proportion of respondents.

The procedures for applying this sampling method are addressed in the [Sampling Instructions](#) and done using the [sample construction workbooks](#). **It is important these instructions are strictly adhered to and that the sample construction workbooks provided by the Survey Coordination Centre are used to draw your sample. They will ensure you sample correctly. Incorrect sampling will delay a trust entering fieldwork as they will have to resample.**

### Additional mailing materials

As well as the materials stated for inclusion in mailing packs in the [implementing the survey](#) document, an information sheet for children and young people will also need to be included in the **first and third mailing packs**. There are two versions of this information sheet, one designed for 8-11s for use with the survey version 'B' questionnaire and one designed for 12-15s for use with the survey version 'C' questionnaire. Both of these information sheets should be available by November and will be found [here](#).



## Data protection, confidentiality and Section 251

This survey has received approval under Section 251 of the NHS Act 2006. A copy of the Section 251 approval letter can be found on the NHS Surveys website here:

<http://nhssurveys.org/survey/2269>

When carrying out your survey, you will need to ensure that you comply with the [General Data Protection Regulation 2018 \(GDPR\)](#), and [ensure that all responses are kept confidential](#).



### General Data Protection Regulation (GDPR)

Changes in the law governing the management and use of patient data went into effect 25<sup>th</sup> May 2018. [The GDPR](#) replaces the Data Protection Act 1998.

If your trust has implemented operational changes as a consequence of the GDPR and you think these changes will impact how you sample and how you share data, please contact the [Survey Coordination Centre](#).

You will also need to comply with the [NHS Code of Practice on Confidentiality](#), which incorporates the [Caldicott principles](#). You should take particular care to ensure that your use of patient data in carrying out the survey complies with these six principles.

In particular, **you should be aware of the flows of patient data and the issues which these present. If your trust is planning to implement trust-wide opt-in policies, or if your trust already has an opt-in consent mechanism in place**, we ask that you get in touch with the [Survey Coordination Centre](#).

## Ethical issues and ethics committees

NHS organisations in England looking to undertake research follow a process of [seeking approval from the Health Research Authority](#) (HRA). Although the NPSP is considered a service evaluation and therefore does not require approval, every survey within the programme applies for [ethical approval](#) to comply with best practice.

All the changes made to the 2018 Children and Young People's Patient Experience Survey (questionnaire, covering letters and information sheet) have received [NHS ethics approval](#). A copy of the ethics approval letter is available here: <http://nhssurveys.org/survey/2270>

## Research governance requirements

The [UK Policy Framework for Health and Social Care Research](#) sets out the principles of good research governance and aims to ensure that health and social care research is conducted to high scientific and ethical standards. It spells out standards and the responsibilities of various parties

involved in research. CQC has produced [a table](#) that sets out the responsibilities of organisations providing care and the arrangements made by CQC for patient surveys.

## Collecting data from non-English-speaking populations

Patients who respond to your survey should be representative of all individuals who use the trust, so it is paramount that groups with a limited understanding of English are not excluded. There are a number of strategies that you can use to ensure you collect the views of [people with a limited understanding of English language](#).

## Timetable

The survey fieldwork period for this year's survey is 18 weeks. The best way to optimise the length of available fieldwork is to:

- Generate your sample promptly and within the recommended two week sample drawing period.
- Respond to queries as quickly as possible to avoid unnecessary delays.
- Mail out questionnaire packs promptly once permission has been received (contractors and in-house trusts only).

Details on what should be included in each of the mailings **in addition to the Children and Young People's Patient Experience survey-specific materials** (see 'Additional mailing materials'), and how to send them out, are available [on our website](#).

Key dates for the 2018 are shown below. Check in the left-hand column to see if a given date applies to you.

Key dates		
Trusts	Deadline for informing the <a href="#">Survey Coordination Centre</a> of your chosen contractor (or if you will be running the survey in-house)	2 November 2018
Trusts	Trust webinars	8 November 2018 4 December 2018
Contractors and In-house trusts	Deadline for emailing <b>PDF copies</b> of questionnaires and covering letters to the <a href="#">Survey Coordination Centre</a>	4 January 2019
Contractors and In-house trusts	Deadline for delivering <b>hard copies</b> of questionnaires and covering letters to the <a href="#">Survey Coordination Centre</a>	18 January 2019
Trusts	Trusts draw their sample	14 January – 25 January 2019
Trusts	Deadline for submitting sample to contractor	Set by contractor
Contractors and In-house trusts	Samples checked by Survey Coordination Centre	28 January – 8 February 2019

Contractors and In-house trusts	Deadline for submitting samples the Survey Coordination Centre	8 February 2019
All	Start of fieldwork	11 February 2019 <sup>1</sup>
Contractors and In-house trusts	Start of weekly monitoring	14 February 2019
Contractors and In-house trusts	Final weekly monitoring report due	13 June 2019
All	Close of fieldwork	14 June 2019
Contractors and In-house trusts	Deadline for submitting final response data to Survey Coordination Centre	21 June 2019

## Compiling a list of patients

You are required to follow the [sampling instructions](#) published for this survey. If data is excluded because major sampling errors are detected, this will impact on the assurances that organisations can have about the experiences of your patients. In 2016, seven major errors were identified, but were able to be rectified in time for the trusts concerned to be able to take part. More information on these errors can be found in the 2016 survey's [sampling errors report](#).

Your sample should only be used for the purposes of distributing the 2018 Children and Young People's Patient Experience Survey. This is because the precise use of the sample collated for the survey has received ethical approval and Section 251 approval for the survey only. Any additional use of the sample would therefore require a separate ethics application and information governance approval.

Once you draw your sample of eligible patients, this list must be locally checked for deceased patients and it must be submitted for DBS (Demographic Batch Service) checks. This is to check for any patients who may have died since they were discharged from your trust. Before mailing two, submitting for DBS checks is not required, however a local check must still be conducted. Before mailing three, you must do one of the two checks – local checks or DBS checks – and it is up to the trust to decide which they would rather do. Please ensure you read the sampling instructions carefully on how to submit your file to DBS and how to remove deceased patients.

## Publicising the survey

The best way to ensure your survey is a success is to ensure that you involve those people who have the most impact on patients experience and who will be responsible for responding to the results of the survey. We recommend that you [keep everyone in your trust informed](#).

In addition, it is a requirement as per [Section 251](#) approval that your trust advertise the upcoming survey during the sampling period (1<sup>st</sup> November to 31<sup>st</sup> December 2018). This can be done by putting up the **mandatory [dissent poster](#)** and optional [flyer](#) in all the relevant places. These

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<sup>1</sup> Please note that trusts who submit and have their samples approved by the Survey Coordination Centre prior to the start of fieldwork will be permitted to start mailing prior to the 11<sup>th</sup> February 2019.

materials allow patients to be aware of the survey and provide them with an opportunity to ask questions or give dissent if they wish to be excluded from taking part.

## Practicalities of implementing the survey

You can find information and advice on printing the survey materials, setting up a PO box and a Freepost address, sending out the survey packs, and booking in questionnaires in the [Implementing the survey: practicalities](#) advice sheet.

## Entering and submitting final data

Final data must be submitted to the Survey Coordination Centre uncleaned and checked using the [data checklist](#) and [data entry spreadsheet](#) provided.

Response data must be entered following the coding rules described in the [entering and submitting final data](#) guidelines. This includes guidelines on how to code missing responses, free-text comments and multiple choice questions. The completed data entry spreadsheet **must not** be emailed, instead it must be password protected and submitted [via our FTP](#).

## Making sense of the data

The usefulness of your survey data will depend on having a clear improvement programme in place and on how well you are able to make use of the data. The fundamental steps of understanding and interpreting data usually involve:

- Examining the number of patients and or their parents/carers giving each response to a question.
- Analysing the data by particular groups of patients (e.g. males/females, different long-term conditions), different areas of care (e.g. hospital staff, operations and procedures), or other information (e.g. treatment function code).

You can find further advice and suggestions tailored to the surveys within the NPSP in the [Making sense of the data](#) document.

## Reporting results

Just as important as the analysis, development and the execution of the survey is the presentation of the data. How you focus, design and present a report will go on to facilitate the use of the data collected into real actionable outcomes. You may like to consider the suggestions proposed in [Reporting results](#) to help you decide which issues to focus on in your report.

## Questions?

If you have any questions, please contact the Survey Coordination Centre at:

[cyp@surveycoordination.com](mailto:cyp@surveycoordination.com)

01865 208127