

Children and Young People's Patient Experience Survey 2020

Trust webinar

Agenda

- Changes from 2018 survey [25 mins]
- Questionnaire development [10 mins]
- Data Protection and Section 251 Requirements [5 mins]
- Instruction Manuals [5 mins]
- Sampling procedure and example [10 mins]
- Practical example of how to draw a sample [15 mins]
- Potential Sampling Errors [5 mins]
- DBS checks [5 mins]
- Entering fieldwork [5 mins]
- Key dates [5 mins]
- Questions

Changes from 2018 Survey

Sampling Extension

The sampling period for CYP20 will be extended to January, meaning **ALL TRUSTS** will need to sample from **1st November 2020 to 31st January 2021**

- The second wave of the COVID-19 pandemic has resulted in an estimated 35% drop on average across participating trusts
- If we do not sample into January, the quality and value of the survey will be impacted. Far fewer trusts are likely to be able to draw full samples than in 2018 (likely just 29) and nearly five times as many trusts will not be able to draw the minimum number of 400
- Extending the sampling period mitigates the impact of admission drops on sample sizes. Sampling into January will mean all trusts have similar sample sizes to 2018

Sampling Extension

Key information for trusts:

- **ALL trusts** must sample eligible patients from November – January, including larger trusts. A failure to do so is a Section 251 breach
- Dissent posters must stay up throughout January
- Eligible patients will have been discharged between 1st November and 31st January 2021, and aged between 15 days and 15 years at the time

Sample Variables

- Three new sample variables are required
 - Mobile phone indicator
 - COVID-19 diagnosis
 - Suspected/treated as COVID-19
- Postcode is required for analysis purposes for 2020
- COVID-19 Attribution file accepted should trusts not be in a position to supply data in the main sample file

Changes to Cover Letters

- GDPR text on reserve side of the 1st and 3rd covering letters
- Added note to request Easy Read, large print or braille versions of the questionnaire.
- The 1st and 3rd covering letters for the 8-15 group will address ‘you and your child’ in both the main body of covering letter and FAQ section.
- Email helpline contact added

Dissent posters

- Must be displayed November 2020, December 2020 and **January 2021**
- Available in 12 languages, English and 11 other common languages in England
- Available in Word format
- Dissent posters should **remain on display during the month of January**
- Any trusts who need to sample in October should have displayed the dissent posters in October

Questionnaire development

Development Procedure

- Desk research identifying developments in policy
- Analysis of questionnaire performance using 2018 data
- Recommendations of CYP and professional Advisory Groups
- Cognitive testing with 18 parents whose children have recently been admitted to hospital, as well as 9 children (aged 8-11) and 9 young people (age 12-15) who have recently been admitted to hospital.
- Gender questions redeveloped following:
 - Desk research, stakeholder workshops and cognitive interviews with patients and their parents as well as cisgender and non-cisgender young people

Questionnaire overview

- The questionnaire for parents of 0-7 year olds consists of 55 questions on 8 pages.
- The questionnaire for 8-11 year olds consists of 65 questions on 8 pages.
 - The first section is for the child and contains 24 questions over 3 pages.
- The questionnaire for 12-15 year olds consists of 67 questions on 8 pages.
 - The first section is for the child and contains 27 questions over 3 pages.
- The questionnaires are copyrighted and therefore must not be altered in any way e.g. trust logos are not to be added

Questionnaire changes 0-7 years

One new question: Q12

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

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

Modifications to two questions: Q24, Q34 (note added)

- Note added to 'About your child' section
- Redeveloped gender question.

Questionnaire changes 8-11 years

Two new questions: Q11, Q30

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
- Don't know / can't remember

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

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

Questionnaire changes 12-15 years

Three new questions: Q11, Q24, Q33

This question might be important for children and young people that frequently visit hospital for ongoing care. 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?

- Yes
- Sort of
- No
- I'm not moving to adult services
- I don't know if I'm moving to adult services

Gender question redevelopment

Parents questionnaire

49. What best describes your child's gender?

- 1 Female
- 2 Male
- 3 A gender not listed here _____
- 4 Prefer not to say

Children's questionnaire

24. What best describes your gender?

- 1 Girl
- 2 Boy
- 3 Something else _____
- 4 Don't want to say

Young people's questionnaire

26. What best describes your gender?

- 1 Female
- 2 Male
- 3 Non-binary
- 4 A gender not listed here _____
- 5 Unsure how to describe myself
- 6 Prefer not to say

61. What sex was your child assigned at birth?

- 1 Female
- 2 Male
- 3 Intersex
- 4 Prefer not to say

27. Is your gender the same as the sex you were given at birth?

- 1 Yes
- 2 No
- 3 Prefer not to say

Accessible questionnaires

- Easy Read and Large Print version
 - Upon request from a patient the contractor will need to print the questionnaire and send to the patient.
- Braille version
 - Upon request for a braille version of the questionnaire, contractors will need to contact designated specialist sub-contractor (printer) to request a braille questionnaire.
 - No patient identifiable data should be shared with the specialist printer
 - The specialist printer will then send the printed Braille questionnaire to the approved contractor
 - A accompanying cover letter will also be produced in braille
 - Before sending the pack to the patient, the contractor will need to print the mailing information onto the covering letter.

Accessible questionnaires: In-house trusts

- The number of accessible questionnaires completed will be monitored during fieldwork using the outcome codes below.
- This will allow contractors and in house trusts to distinguish between the various accessible versions for data submission. Both braille and large print completed questionnaires are comparable and should be included in the main SPSS dataset. However Easy Read response data is not comparable and should be submitted in a different dataset.
 - 8= Easy Read completed questionnaire
 - 9= Braille completed questionnaire
 - 10= Large print completed questionnaire

Data Protection and Section 251 Requirements

General Data Protection Regulation (GDPR).

How patient's personal data is being protected under the new GDPR has been stated on the reverse side of both covering letters 1 and 3.

Is my information secure?

You and your child's personal data are held in accordance with the General Data Protection Regulation, Data Protection Act 2018 and the NHS Confidentiality Code of Practice. If you would like more information about how [NHS trust name] or CQC use your personal information to keep it safe, and what your rights are under the law, please write to us, call [Freephone survey number], email [XXXXXXXXXXXX@XXXXXX.XXX] or see our privacy notice [link to trust privacy notice].

To send out questionnaires to parents, [NHS Trust name] selected a sample of children and young people who had recently used their services. Personal data about your involvement in this survey is not used for any other purpose and is deleted once the survey process is complete. Your answers to the survey are not linked to your name or full address, but researchers analysing the results of the survey will use your postcode to undertake geographical analysis of overall results.

[IF CONTRACTOR USED]: [Your contact details have been passed to [survey contractor], only so that they can send you this questionnaire and process your response. [Survey contractor] will process your answers in confidence and keep them separate from your contact details. [Survey contractor] will delete your contact details once the survey process is completed.

Dissent Poster

- [Dissent posters](#) must be displayed during the sampling months of November and January 2021
- We request you [publicise](#) the survey both internally and externally to ensure patients are aware of the survey and have the opportunity to opt-out should they wish.
- Posters are not to be altered in any way
 - Doing so would invalidate the survey's Section 251 approval.
- In the box provided, a telephone number must be provided. In addition, an email and a postal address should be provided if they are available.
- Ensure a log of patients who have dissented from taking part in the survey is accurately kept. You will need to document this number on your sample declaration form.

National Data Opt Out Programme

- NPSP received exemption from National Data Opt-out Programme
- Continued separate opt-out mechanisms
- Patients **do not** have to actively consent to the sharing of their data (for the Children and Young People's Experience Survey)

Instruction Manuals

Instruction Manuals - Survey Handbook

For survey leads

- Brief document
- Survey specific
- Key summary document that [links](#) to all other relevant information:
 - What's new for this year/survey
 - Tips on managing the survey
 - Key dates: Top level
 - Highlights on key information (Section 251, etc.)

Instruction Manuals - Sampling Instructions

For sample drawers (data team)

- Detailed information

Three changes for 2020:

- Additional sample variables: **mobile phone indicator, COVID-19 diagnosis and suspected/treated as COVID-19**
- Sample period extended: **November 2020 - January 2021**
- Survey specific
- Step-by-step instructions on how to draw sample
- Flowchart
- [Links](#) to relevant content

Generic NPSP Instruction Documents

Separate PDF documents on the [NHS website](#)

- Patient feedback and the NHS Constitution
- Setting up a project team
- Data protection and confidentiality
- Ethical issues, ethical committees and research governance
- Collecting data from non-English speaking populations

- Publicising the survey
- Implementing the survey – practicalities
- Submitting samples
- Entering and submitting final data
- Making sense of the data
- Reporting results
- Universal glossary

Sampling Procedure

Sampling Procedure

- Sampling process for CYP 2020 is the same method used in 2018 and different to other patient surveys.

Population Sampled

- **ALL** eligible **admitted patients** discharged from your trust between **1st November 2020 and 31st January 2021**, who were aged between 15 days and 15 years (inclusive) at the time of their discharge.
- Initial list must be all discharges (including duplicates – these are removed later)

Systematic Stratified Sampling Method

- Enables trusts to increase the number of patients aged 8-15 in their sample, above what would be possible if the patients in their sample were consecutive discharges.
- Sample size = 1250 unique patients per trust
- Fixed quota of patients from each age group if >1250 patients
 - 450 parents of children aged 0-7 years
 - 400 children aged 8-11 years
 - 400 young people aged 12-15 years

Sample variables – New for 2020

- **Full postcode:** As in 2018, this should be included within the sample file for SCCEM to check. We are analysing the data by postcode for 2020 so this field is required.

Additional sample variables requested for 2020:

- **Mobile phone indicator:** to identify if trusts hold a mobile phone number for parent/carer of patients
 - 0 = do not have mobile phone number of parent/carer of patient (or there is a telephone number present but you suspect it is a landline)
 - 1 = have mobile phone number for parent/carer of patient
 - 9 = unsure
 - 99 = unable to identify if contact details are parents or child's

Sample Variables - New for 2020

- **COVID-19 diagnosis** (SCCMEM and CQC recommend this be derived from ICD-10 codes U07.1 COVID-19, virus identified and U07.2 COVID-19, virus not identified. Note: some trusts may have upgraded to using ICD-11 codes. If that is the case, those trusts would create this variable from using ICD-11 RA01.0 COVID-19, virus identified and RA01.1 COVID-19, virus not identified)
 - 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

We are not requesting the transfer of ICD-10 data to either the SCCEM or approved contractors. NHS Trusts will use the ICD-10 information to create the Covid-19 diagnosis variable above

- **Treated as a suspected or confirmed COVID-19 case** (derived from trust locally held records)
 - 1= Treated as confirmed or suspected Covid-19
 - 2= Treated as non Covid-19
 - 3= Status unknown

Sample Variables - New for 2020

- Trusts should be asked in the first instance to submit COVID-19 indicator as part of sample file.
- Aware that some trusts may experience clinical coding delays. In these cases trusts should submit a separate attribution file directly to the SCCEM, via FTP, containing the following variables:
 - NHS Trust code
 - Patient Record Number (PRN)- the unique identifier code for each sampled patient
 - COVID-19 diagnosis (derived from ICD-10 codes)
 - Treated as a suspected or confirmed COVID-19 case

Free Text Comments

- All free-text comments will be included in the final data submitted to the Survey Coordination Centre
- Free text comments are **NOT** anonymised – wording in questionnaire permits this
- Trusts can exercise discretion if staff members are named however all patient feedback is to be respected and noted accordingly

Sampling Procedure - Exclusions

- Patients who indicated dissent for the 2016 survey
- Private patients (non-NHS)
- NHS patients treated at private hospitals
- Any patients who are known to be current inpatients
- Ward attendees - exclude those patients who visited the ward (eg: for a blood test) but were not admitted as a day case or did not have an overnight stay as an inpatient
- Patients without a UK postal address (but do not exclude if addresses are incomplete but useable, e.g. no postcode)
- Any patient, parents or carers known to have requested their details are not used for any purpose other than their clinical care (patients that have indicated dissent).

Sampling Procedure - Exclusions

- Deceased 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
- Newborn babies where the mother is the primary patient (ie: 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

Systematic Stratified Sample

| | | | | | | | | | |
|----|----|----|----|----|----|----|----|----|-----|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 |
| 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 |
| 31 | 32 | 33 | 34 | 35 | 36 | 37 | 38 | 39 | 40 |
| 41 | 42 | 43 | 44 | 45 | 46 | 47 | 48 | 49 | 50 |
| 51 | 52 | 53 | 54 | 55 | 56 | 57 | 58 | 59 | 60 |
| 61 | 62 | 63 | 64 | 65 | 66 | 67 | 68 | 69 | 70 |
| 71 | 72 | 73 | 74 | 75 | 76 | 77 | 78 | 79 | 80 |
| 81 | 82 | 83 | 84 | 85 | 86 | 87 | 88 | 89 | 90 |
| 91 | 92 | 93 | 94 | 95 | 96 | 97 | 98 | 99 | 100 |

- Systematic sampling within each “strata”, or age group
- A different sampling interval will be calculated for each age group
- The workbook will calculate these automatically
- Putting the correct patients into workbook 1 is **very important**

Sampling Procedure

Use two sampling workbooks

[CYP20 Sampling Workbook 1](#)

Tab 1:

- Create list of attendances
- Remove duplicates
- Checks (trust checks, DBS checks)
- Sort list (gender > year of birth > month of birth)

Tab 2:

- Create the sample (max 1250)
- Quota for each group: 450/400/400
- NB - If quota not met for one or two groups, the number in the other group/s may be higher than quota

Enough eligible cases

If your trust has enough eligible cases for all three survey versions:

- The total sample size will be 1250, made of 450 cases for version A, 400 for version B, and 400 for version C. For example:

| | |
|----------------------------|------|
| Number in list | |
| Survey version A (0-7s): | 824 |
| Survey version B (8-11s): | 583 |
| Survey version C (12-15s): | 649 |
| Ineligible dates: | 0 |
| Number in sample | |
| Survey version A (0-7s): | 450 |
| Survey version B (8-11s): | 400 |
| Survey version C (12-15s): | 400 |
| Total sample size: | 1250 |

Fewer than or exactly 1250 eligible cases

If your trust has fewer than or exactly 1250 eligible cases in total:

- All cases should be included in your sample, meaning the 'number in sample' section will match the 'number in list' section. For example:

| | |
|----------------------------|-----|
| Number in list | |
| Survey version A (0-7s): | 516 |
| Survey version B (8-11s): | 269 |
| Survey version C (12-15s): | 141 |
| Ineligible dates: | 0 |
| Number in sample | |
| Survey version A (0-7s): | 516 |
| Survey version B (8-11s): | 269 |
| Survey version C (12-15s): | 141 |
| Total sample size: | 926 |

More than 1250 eligible case, but less than the target sample size for one or two groups

If your trust has more than 1250 eligible cases in total, but less than the target sample size for one or two of the survey versions:

- All patients from the survey version(s) with less than the target number of cases will be included.
- The workbook will automatically increase the number of cases from the survey version(s) with excess patients, selecting a total sample size of 1250 cases. For example:

| | |
|----------------------------|------|
| Number in list | |
| Survey version A (0-7s): | 229 |
| Survey version B (8-11s): | 285 |
| Survey version C (12-15s): | 1108 |
| Ineligible dates: | 0 |
| Number in sample | |
| Survey version A (0-7s): | 229 |
| Survey version B (8-11s): | 285 |
| Survey version C (12-15s): | 736 |
| Total sample size: | 1250 |

Sampling Procedure

[CYP20 Sampling Workbook 2](#)

- Finalise sample
- Checks
- In house trusts: split mailing and sample data

Submitting data

- Complete sample declaration form and wait for approval
- Trusts using contractors: share with contractor
- In-house trusts: share only sample data file with Survey Coordination Centre

Sample Declaration Form

- The Sample Declaration Form is an excel sheet
- Person drawing the sample completes the form
- Caldicott Guardian reviews the form and indicates their approval to transfer the data
- The Caldicott Guardian should complete two tabs - the 'Declaration Agreement' and 'SMS Reminders'
- Form is then emailed to your approved contractor with the Caldicott Guardian copied into the email (emailed to the Survey Coordination Centre if conducting the survey in-house).
- Data is not to be transferred until your contractor approves the form (or to the Survey Coordination Centre if conducting the survey in-house)

In-House Trusts: Separating mailing and sample data

- After [Sample Declaration Form for In-House Trusts](#) is approved, then trusts may submit a sample file **containing ONLY sample data** to the Coordination Centre.
- Sample file **must always be submitted via a secure FTP and never via email**.

Trusts Using a Contractor: Single mailing and sample file

- After [Sample Declaration Form for Trusts Using a Contractor](#) is approved, then trusts may submit a combined mailing and sample data sample file to their approved contractor.
- Sample file **must always be submitted via a secure FTP and never via email**.

Practical example of drawing your sample

Potential Sampling Errors

Implications of Major Errors

Survey data is used by the CQC to monitor quality of care within each provider. If a major error occurs and it cannot be rectified, implications are as follows:

- The lack of assurance would be flagged as a warning to inspectors against your trust
- No data would be provided to NHS England for your trust's Overall Patient Experience Scores
- No historical comparisons would be provided for your trust in the current survey report if a major error is found to have occurred in your 2020 data

For detailed information on sampling errors see the [2018 report](#).

The **Sample Declaration Form** can help you avoid errors. Avoiding errors will ensure your questionnaires can be mailed out earlier and your data will be usable in this year's survey.

Potential Errors

Please check that you have included:

- ALL eligible admitted patients discharged from your trust between 1st November 2020 and 31st January 2021, who were aged between 15 days and 15 years (inclusive) at the time of their discharge
- Patients whose address is incomplete, but contains enough information to have a reasonable chance of being delivered
- Patients who have addresses outside England but inside the UK (military personnel, Wales, Scotland, Northern Island, Isle of Man...)
- Gynaecology patients if their visit was unrelated to pregnancy.

Please ensure that you submit your sample data using a secure FTP and NEVER via email. This constitutes a Section 251 breach and CQC will be informed immediately.

Potential Errors

- Unusual age and gender distribution may indicate that eligible patients have been excluded in error
- Submitting files to the Coordination Centre that are not fully anonymised (including full date of birth displayed as only the year)
- Not drawing the sample from the full sampling period. Using consecutive discharges instead.
- Patient Record Number in incorrect format
- Missing/invalid NHS Site codes
- Incorrect codes in ethnic category

DBS Checks

- Before mailing 1:
Demographic Batch Service (DBS) checks are **required** along with local checks for deceased patients
- Before mailing 2:
Only local checks are required. DBS checks are recommended.
- Before mailing 3:
Local checks are required. DBS checks are strongly recommended.

Entering fieldwork

Entering Fieldwork Early/ On Time

Entering fieldwork on time or earlier will enable your trust to maximise responses from younger and Black and minority ethnic (BME) groups. You will also likely receive an overall higher response rate, providing your trust with more data.

- Ensure you have a **survey team** in place **before** you start drawing your sample
- Generate your sample promptly: begin preparing now and start drawing on **8th February**.
- Respond to **queries** as soon as possible to avoid unnecessary delays
- Ensure there is sufficient **resourcing** around the time of drawing your sample and answering queries – communicate with your team, handover tasks if people are going to be on leave and let your contractor and the survey coordination centre know any updates.
- If there are any changes in the **survey lead**, inform your contractor and the coordination centre.

Key dates

Key dates

| Deadline/Event | Date |
|--|---|
| Trusts draw their sample | 8 th February – 19 th February 2021 |
| Deadline for submitting sample to contractor | Set by contractor |
| In-house trusts deadline for submitting samples the Survey Coordination Centre | 5 th March 2021 |
| In-house trusts submit PDF copies of questionnaires and mailing materials | 1 st February 2021 |
| In-house trusts submit paper copies of questionnaire and mailing materials | 15 th February 2021 |
| In-house trusts submit completed copies of questionnaires | 7 th May 2021 |
| Fieldwork | 8 th March 2021 – 9 th July 2021 |
| Weekly monitoring | Every Thursday during fieldwork, starting 10 th March 2021 |
| Deadline for final data | 16 th July 2021 |

Questions?

Thank you for your time

- Copy of the slides:

<https://nhssurveys.org/surveys/survey/01-children-patient-experience/year/2020/>

- Contact us:

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