Children and Young People's Patient Experience Survey 2018

Trust webinar

Survey Coordination Centre

CareQuality Commission

Agenda

- Survey overview and development
- Data protection and Section 251 requirements
- Survey practicalities
- Sampling procedure
- Potential errors
- Timetable
- Questions and answers

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Survey Overview and Development

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Survey Overview and Development

- ✓Sampling months: November and December 2018
- ✓Sample size (N=1,250)
- ✓Systematic Stratified Sampling Method
- ✓Changes to questionnaire
- ✓Faster first reminder
- ✓Revised instruction manuals

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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

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Questionnaires

- ✓ The questionnaire for parents of 0-7 year olds consists of 54 questions on 8 pages.

- ✓ The questionnaire for 8-11 year olds consists of 62 questions on 8 pages.
  - The first section is for the child and contains 23 questions over 3 pages.

- ✓ The questionnaire for 12-15 year olds consists of 63 questions on 8 pages.
  - The first section is for the child and contains 24 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

- ✓ Revised illustrations for CYP18.

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Faster first reminder

- ✓From the Adult Inpatient 2017 pilot study: One intervention tested resulted in a significant increase in response when compared to the control group. This was a faster reminder following the initial mailing.

- ✓Overall 40.8% of those who received the standard survey materials responded to the survey. The early postal reminder gave rise to a response rate of 44%.

- ✓This will be adopted for the CYP18 survey.

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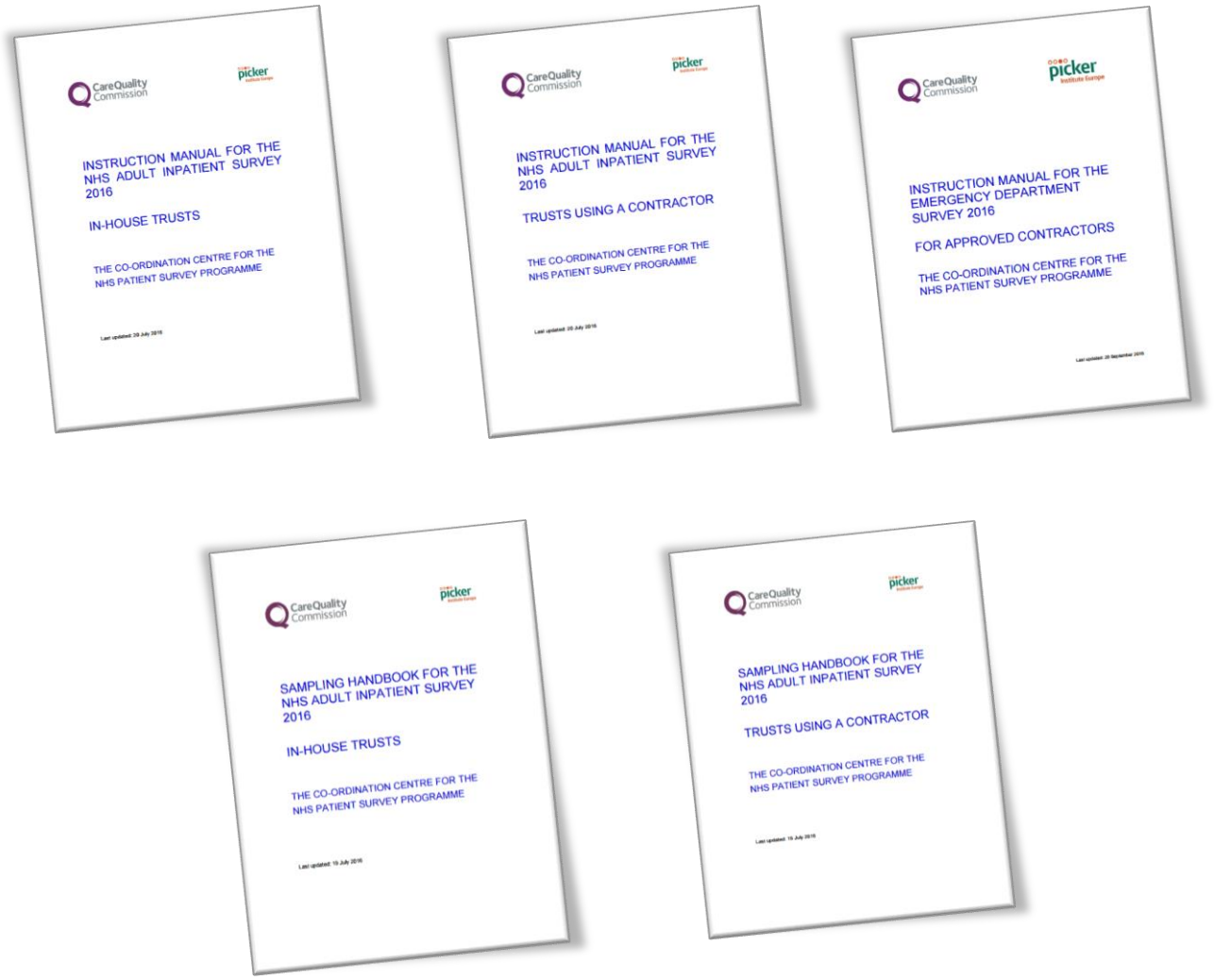
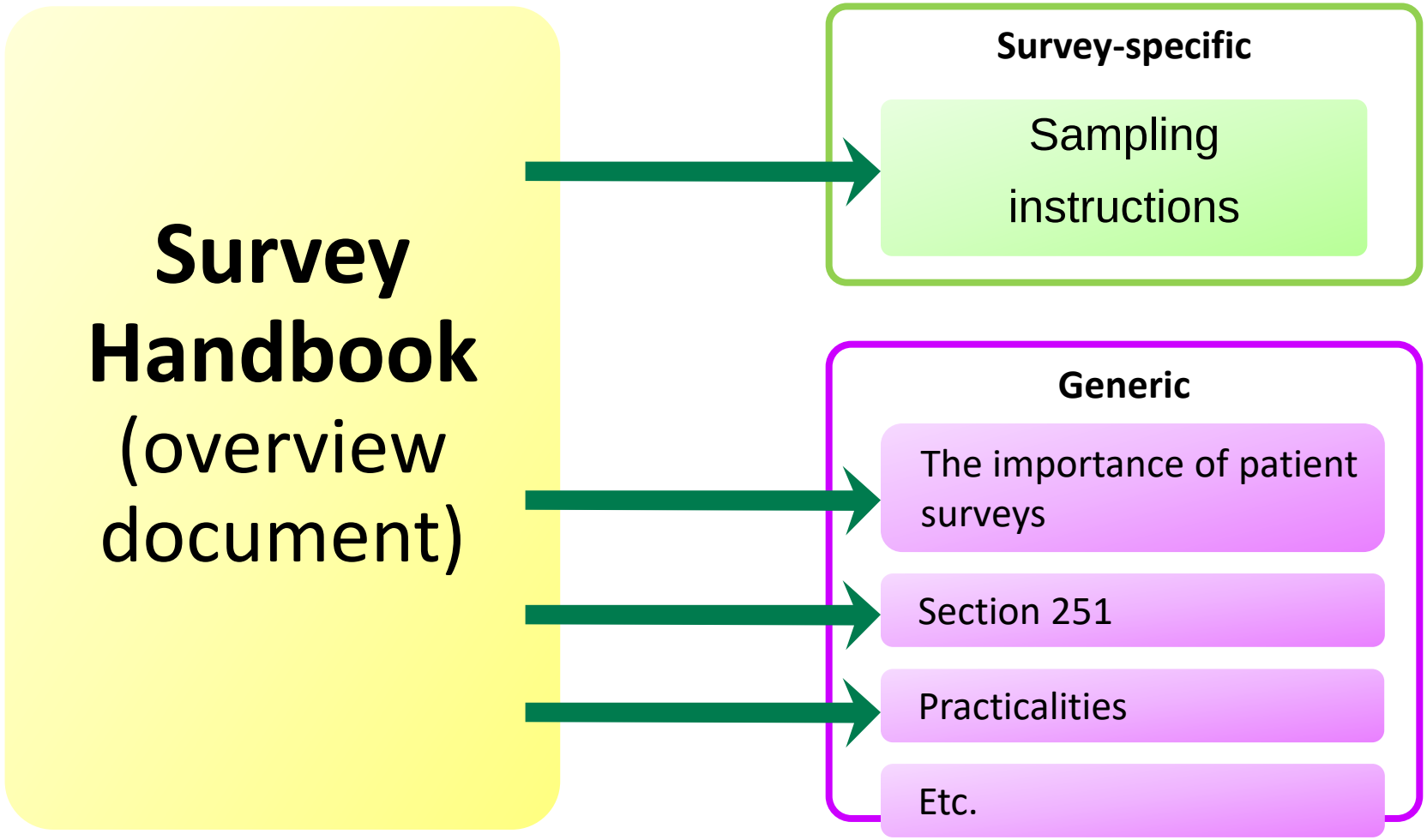
Instruction Manuals

Instruction Manuals - Old Structure



Instruction Manuals - New Structure



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
  - Key dates: Top level
  - Highlights on key information (Section 251, etc.)

Instruction Manuals - Sampling Instructions

For sample drawers (data team)

- Detailed information
- Survey specific
- Step-by-step instructions on how to draw sample
- Flowchart
- **Links** to relevant content

Generic NPSP Instruction Documents

Separate PDF documents on

http://www.nhssurveys.org/usefullinks

1) The importance of survey feedback
2) Setting up a project team
3) Data protection and confidentiality
4) Ethical issues, ethical committees and research governance
5) Collecting data from non-English speaking populations
6) Publicising the survey
7) Implementing the survey – practicalities
8) Submitting samples
9) Making sense of the data
10) Reporting results
11) Universal glossary

Data protection

General Data Protection Regulation (GDPR).

- GDPR came into force on May 25, 2018.
- 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.
- For an in-house trust this states:

How is my personal data protected?

Your personal data are held in accordance with the General Data Protection Regulation and the NHS Confidentiality Code of Practice. If you would like more information about how [trust name] or we use your personal information to keep it safe, and what your rights are under the law, please write to us, call [Freephone survey number] or see our privacy notice [link to trust privacy notice].

To send out questionnaires to patients, [trust name] selected a sample of 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 responses are not linked back to your name, or to any other personal data that may identify you.

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General Data Protection Regulation (GDPR).

- For trusts using a contractor, this states:

How is my personal data protected?
Your personal data are held in accordance with the General Data Protection Regulation and the NHS Confidentiality Code of Practice. If you would like more information about how [trust name] or we use your personal information to keep it safe, and what your rights are under the law, please write to us, call [Freephone survey number] or see our privacy notice [link to trust privacy notice].

To send out questionnaires to patients, [trust name] selected a sample of 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 responses are not linked back to your name, or to any other personal data that may identify you.

[[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].]

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“Section 251” Approval: Processing Identifiable Information

Approval for the Survey

- ✓Approval under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process patient identifiable information without consent.

- ✓Granted by the Confidentiality Advisory Group (CAG) at the Health Research Authority on behalf of the Secretary of State; allows the common law duty of confidentiality to be put aside in order to enable the processing of patient identifiable information without consent.

- ✓The NHS Patient Survey Programme is presently **exempt** from the National Data Opt-out Programme.

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Processing identifiable information: Approval for the survey

- ✓ Provides a legal basis for trusts using a contractor to provide names and addresses to them

- ✓ In-house trusts – though information is not shared, standard practices and procedures must be followed to protect confidentiality and meet Data Protection Act and GDPR requirements

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Section 251: Adherence to approval

✓Follow methodology in sampling instructions. Particular importance:

- Recording dissent and removing patients; Sample declaration form and process.

Any deviation from the methodology outlined in the survey instructions may render the support invalid - CQC is obliged to take a number of steps

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Processing identifiable information: Recording dissent

- ✓Dissent posters must be displayed to patients and their parents/carers. Dissent is to be logged in a consistent manner;
- ✓As data controller, the Trust must be satisfied that appropriate dissent mechanisms are in place;
- ✓Trusts to display the dissent poster during the sampling period, allowing potential respondents to opt out of the survey. The posters are available in a number of languages, and can be found here:

  http://nhssurveys.org/surveys/1362

- ✓Patients who have indicated dissent must not be included in the sample

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Processing Identifiable Information: Sample File Information

- ✓Trusts using a contractor MUST NOT split the file, contractors will do this at a later stage.

- ✓Trusts conducting the survey in-house **must** still split their sample and mailing data.

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Survey Practicalities

Survey publicity and raising awareness

- ✓ It is important that the national surveys are publicised and responses encouraged so that as many patients' voices are heard as possible.
- ✓ Think about how your trust communications team might be able to support you in this task.
- ✓ More information and communication templates are available here:

http://nhssurveys.org/usefullinks

- ✓ CQC are keen to get feedback on the success of any promotional activities to help develop our approach to raising awareness across the NHS Patient Survey Programme. Send your feedback to **Patient.Survey@cqc.org.uk**

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Administration of the Survey

✓Trusts may conduct the survey:

- In-house
  or
- Use an approved contractor

✓A list of approved contractors is located on the NHS Surveys website:
http://www.nhssurveys.org/approvedcontractors

✓Trusts must notify the Survey Coordination Centre of who is carrying out the survey. **If you haven't done so, please inform us ASAP.**

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Adherence to Survey Instructions

✓ Sampling instruction manuals set out procedures dictated by Section 251 and Research Ethics approval:

- Section 251 = A legal basis for trusts using a contractor to provide names and addresses to them.
- It is not permitted to offer financial inducements or lottery prizes to respondents.
- It is not permitted to translate the questionnaire into other languages.

✓ Adjustments to the method or materials set out in the Survey Handbook and Sampling Instruction manuals:

- Seek local research ethics approval **and** check with the Survey Coordination Centre the proposed alteration(s) would not compromise comparability

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Fieldwork timekeeping

- ✓Delays in entering fieldwork = reduced response rates.
- ✓Ensure you submit your sample declaration form and sample data in an accurate and timely manner.
- ✓**It's crucial to get both the sample declaration form and sample file right first time to avoid delays**
- ✓Consider allowing time and resources to respond to queries from the Survey Coordination Centre or contractor so you enter fieldwork as soon as possible.

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DBS checks

- ✓DBS checks are required as part of the sampling process.
- ✓Checking trust's own records = reliable and up-to-date record of deceased patients.
- ✓You should NOT exclude patients just because it was not possible for DBS to match them on their records. If you did this, you would bias the sample.
- ✓Some recently deceased patients may make it into the sample. Trusts should to be prepared for this.

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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

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Sampling Procedure

Sampling Procedure

- ✓Sampling process for CYP 2018 is the same method used in 2016 and different to other patient surveys.

Population Sampled

- ✓**ALL** eligible **admitted patients** discharged from your 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.

- ✓Initial list must be <u>all discharges</u> (including duplicates – these are removed later)

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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

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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).

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Systematic Stratified Sample

- ✓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**

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Sampling Procedure

Use two sampling workbooks

CYP18 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

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Do **not** share Workbook 1 with contractors **or** Survey Coordination Centre

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

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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

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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

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Sampling Procedure

CYP18 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

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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
- ✓ 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)

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In-House Trusts:
Separating mailing and sample data

- ✓After Sample Declaration Form 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.**

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Trusts Using a Contractor: Single mailing and sample file

- ✓After Sample Declaration Form 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 <u>never via email</u>.**

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Potential Errors

Potential Errors

Please check that you have included:

- ✓ ALL eligible admitted patients discharged from your 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
- ✓ 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.

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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)
- ✓ Sample not submitted for DBS checks
- ✓ 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

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Timetable

Timetable

- ✓**Patient samples** to be drawn and submitted for DBS checks: 14th to 25th January 2019
- ✓**Sample checking by the Survey Coordination Centre:** 28th January to 8th February 2019
- ✓**Fieldwork:** 11th February 2019 to 14th June 2019
- ✓**Weekly monitoring:** Starts 14th February 2019; ends 13th June 2019
- ✓**Final data** due to Survey Coordination Centre: 21st June 2019

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Q&A

Thanks for joining us

A copy of the slides will be made available on the NHS Surveys website:

- http://www.nhssurveys.org/surveys/1351

Contact details:

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