

Survey Handbook

Under 16 Cancer Patient Experience Survey

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The Under 16 Cancer Patient Experience Survey Programme is run by Picker on behalf of NHS England and NHS Improvement

www.picker.org

Picker

Picker is an international charity dedicated to ensuring the highest quality health and social care for all, always. We are here to:

- Influence policy and practice so that health and social care systems are always centred around people's needs and preferences.
- Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
- Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people's feedback.

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For more information about the Under 16 Cancer Patient Experience Survey, please visit the survey website:

<http://www.under16cancerexperiencesurvey.co.uk>

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Introduction

The Under 16 Cancer Patient Experience Survey is being carried out by the NHS and Picker to understand the experiences of cancer and tumour care among children under the age of 16 and their parents/carers, in England. The results of the survey will be used to understand and improve cancer care both nationally and locally.

The survey was developed after the Independent Cancer Taskforce published its report '[Achieving World-Class Cancer Outcomes: A Strategy for England 2015-20](#)'. The Strategy highlighted the importance of patient experience data in service development and improvement. Although a national survey of cancer patient experience exists in England for adults (the [National Cancer Patient Experience Survey](#)), there was no equivalent programme for children. It was therefore recommended that data was collected on patient experience for under 16s with cancer. This commitment to improvement was also restated in the [NHS Long Term Plan](#).

Survey Information

How was the survey developed?

The survey was developed in 2020 with the support of a wide range of key stakeholders including young patients, parents, clinicians, commissioners, cancer charities and data analysts. An advisory group provided expert advice on the development of the survey.

Who is carrying out the survey?

Picker is carrying out the survey on behalf of NHS England and NHS Improvement. [NHS England and NHS Improvement](#) is the organisation that leads the National Health Service (NHS) in England. [Picker](#) is a healthcare research charity based in Oxford.

The survey testing, fieldwork, analyses and reporting are completed by Picker. You can find out more about Picker on our website: <https://www.picker.org/about-us/>.

What does the survey look like?

The survey asks under 16s and their parents/carers about key areas of their cancer care including information provision, communication and support.

Three surveys have been created for different age groups:

- A survey for parents/carers of 0-7 year olds;
- A survey for 8-11 year olds, with a separate section for their parents/carers to complete;
- A survey for 12-15 year olds, with a separate section for their parents/carers to complete.

The survey will be printed and posted by Picker to the patients' parent or carer. An access code will be printed on the covering letter included with the survey. By entering this unique access code, children and parents can complete the survey online via the survey website if they prefer.

Included with the survey is a multi-language leaflet providing a helpline number where non-English speaking participants can access an interpretation service for help completing the survey, if needed.

Up to two reminders will also be sent to the patients' named parent or carer who have not responded to encourage response. If a patient does not wish to participate in the survey, a Freephone number and email address have been provided in the covering letters to enable them to opt out. They do not need to give a reason for opting out.

Who will be included in the survey?

The survey is sent to a selection of parents/carers of children under 16 who have a confirmed primary diagnosis of cancer or of a non-malignant brain, other central nervous system or intracranial tumour, or non-cancerous blood disease, and who have recently received NHS care and/or treatment (elective and non-elective) in England. This includes those admitted to hospital as inpatients and those seen as day case patients. Both children and parents/carers will be invited to give feedback.

Patients who were diagnosed with cancer a long time ago and have since gone into remission will receive the survey if they have received care or treatment related to their cancer during the sampling period (e.g. if they have had check-ups).

Please note that outpatients and those who received care from Paediatric Oncology Shared Care Units (POSCUs) and other specialist cancer treatment centres are not included. The inclusion of these groups of patients was explored but it was decided to exclude them from the current survey. Outpatients are not included due to the likely manual process that would need to be undertaken to select the correct outpatients at some trusts and subsequent burden of doing so in the current environment. Meanwhile, the reason for deciding to exclude POSCUs and specialist sites was due to the burden of providing a sample in the absence of getting site-level outputs and reports due to low numbers of patients. However, it is recognised that to fully understand experiences of care for children with cancer, we should broaden the inclusion to these groups, which we intend to explore for future surveys.

Has the survey been reviewed by the Data Coordination Board?

The Data Coordination Board have reviewed and approved the survey.

This collection is mandated for all acute cancer services. NHS Foundation Trusts are mandated under schedule 6 of their Terms of Authorisation.

Does the survey have Section 251 approval?

Section 251 approval has been granted by the Confidentiality Advisory Group (CAG) at the Health Research Authority.

The Section 251 approval allows the common-law duty of confidentiality to be set aside and data to be transferred to Picker for the purpose of mailing out materials for the survey.

How will the survey findings be reported?

We will publish a national report of the responses across England, plus reports by Principal Treatment Centres. These will appear on the survey website.

Survey responsibilities

Setting up a project team

The best way to ensure that the survey is a success for your trust is to involve those people who have the most impact on patients' experiences and who will be responsible for responding to the survey results.

As a minimum, you will need the following people involved:

- **A survey lead** – a day to day contact to deal with any queries during fieldwork, and to disseminate results to.
- **A person from your data team**, who will draw your patient sample. You need to share the sampling instructions with them and give them enough time to ensure that the appropriate resources will be in place when the sample needs to be drawn.
- **A member of your clinical cancer team** to check and validate the patient sample.

Advertising the survey and recording dissenters

Participating NHS Trusts should have a system in place to inform patients about the upcoming survey and provide an option for them to opt-out if they don't want to receive the survey. In late 2019, NHS England and NHS Improvement provided trusts with a dissent poster and website wording for displaying in the trust. The posters and/or website information should be displayed during the sampling period. If you are unable to display the dissent poster at your trust, please add this information to your website so that patients are aware of the upcoming survey and have the opportunity to opt-out. A copy of the dissent poster can be found on the survey website:

<https://www.under16cancerexperiencesurvey.co.uk/paedsurvey-support-materials>.

The poster provides basic details of the survey and space to add the contact details of a nominated person within the trust that patients could contact, should they wish to opt-out of the survey. This nominated person may have been the paediatric matron or a member of PALS. The staff member drawing the sample should check with a member of the cancer care team about whose contact details were provided on the dissent poster and reach out to this designated contact regarding opt-outs.

Patients opting out should be advised they are being removed from the mailing list for this survey at this trust only, and not future surveys or other research taking place (either at your trust or other NHS trusts where they may also receive care).

Trusts should have a way to record the details of patients who have opted out, for example using a password protected spreadsheet that is securely shared with the staff member drawing the sample. Patients who have opted out will need to be removed when compiling the patient list before it is submitted to Picker for approval. You will be asked to report how many patients have been removed on the Patient List Declaration Form.

The survey leads will need to work closely with the person who compiles the patient list and check carefully that all patients who have opted out are removed from the sample. The patient list must be signed off by the trust's nominated survey lead before it is submitted to Picker.

Drawing a sample

Trusts are required to draw the patient sample list in accordance with the sampling instructions. These are available here:

<https://www.under16cancerexperiencesurvey.co.uk/survey-support-materials>.

Providing a signature for the survey covering letter

The survey will be accompanied by a covering letter. Trusts are required to provide Picker with the signature they would like to include at the bottom of the covering letter. This may be from the Chief Executive, a Lead Cancer Clinician or a Lead Cancer Specialist. This should be sent to Picker in JPEG format via Picker's [secure file transfer site](#). Please submit these before submitting your sample list, to ensure the trust does not cause a delay in starting fieldwork. The survey will be sent out once all samples have been approved from all trusts.

Keeping everyone informed

Notify as many people as possible about the survey. All cancer departments in the trust should be made aware when a survey is being conducted in case patients ask staff questions about the questionnaire they have received. Survey lead(s) should be prepared to respond to queries quickly. Patients and their parents who may have questions can be directed to the following:

- The survey Freephone number (08000 720 069)

- The survey team email address (under16cancersurvey@PickerEurope.ac.uk)
- The survey website (www.under16cancerexperiencesurvey.co.uk).

What are Picker's responsibilities?

All survey fieldwork will be carried out by Picker. This includes sending out the surveys and reminders, hosting the online survey versions, capturing the survey data, analysing the results and producing reports.

Picker will also undertake deceased checks. The DBS checks will be undertaken at least three times during the fieldwork period: before initial send out; and before each of the two reminders. Picker guarantees that the send out of the initial mailing and the reminders will take place within 24 hours of the relevant DBS deceased check for your trust being received from the service. This arrangement will make the process more efficient and will ensure that the number of deceased patients in the sample will be minimised. It will also reduce the amount of work that trust staff have to undertake. Picker will also inform trusts of the expected mailing dates should they wish to conduct their own local checks for deceased patients prior to the reminder mailings.

Key dates for the survey

Please make the survey team at your trust are aware of the key dates shown in the table below. Delays to samples being submitted will impact on the start of fieldwork. This will lead to data and reports being published later than planned.

Table 1: Key Survey Dates

Dates	Task	Responsibility (Trusts/ Picker)
w/c 11-Jan	Sampling instructions available to Trusts	Picker
19-Jan	Webinar to discuss sampling with Trusts	Picker
25-Jan	Patient list submission start date – date for Trusts to aim toward. (Trusts can submit earlier than this if their list is ready).	Trusts
19-Feb	Last date for patient declaration form and patient sample (with deceased patients removed) to be submitted to Picker. (Trusts should aim to submit in early Feb).	Trusts
25 Jan- 5 Mar	Picker to check samples. Trusts to respond to queries	Picker and Trusts
5-Mar	Final date patient samples can be approved for inclusion in the survey	Picker and Trusts
19-Mar	Patient list finalised	Picker
29-Mar	Picker to conduct DBS trace and send the first survey invite	Picker
12-Apr	Picker to conduct DBS trace and send the first reminder	Picker
26-Apr	Picker to conduct DBS trace and send the final reminder	Picker
28-May	Fieldwork closes	Picker
2-Jun	Analysis and reporting begins	Picker

Submitting your patient list

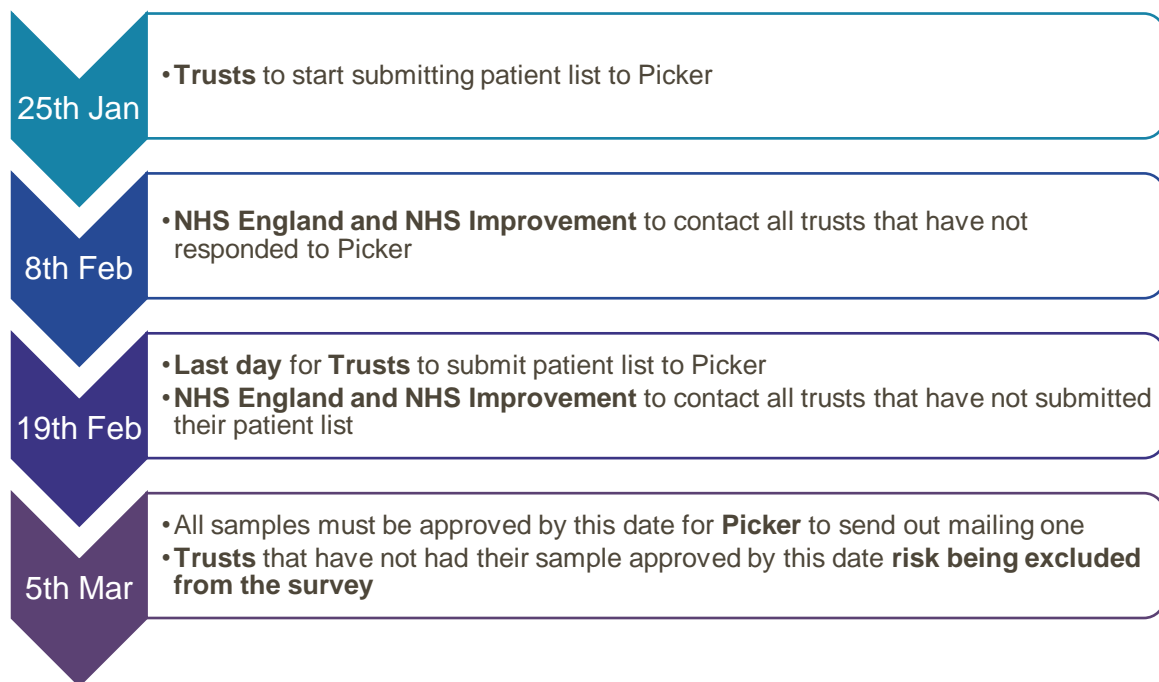
Picker is happy to support you and work with you through any sampling issues and queries you may have during the sampling period. Picker will be in regular contact (via email and phone) from the start of this period until your sample has been approved for mailing. Please do not hesitate to contact us if you should have any questions in the meantime. If there are any issues or delays in submitting your patient list, please contact Picker immediately.

Submission: For the U16 Cancer Patient Experience Survey, there is a deadline for approval of the sample list. Therefore, it is important for you to submit your patient list as early as possible. Approval can take 2-3 weeks due to sample queries and/or resubmissions.

Submitting early will help to ensure that the survey can start on time and that results can be reported back to you in a timely manner.

Patient list queries: It is equally important to respond swiftly to any queries Picker raises regarding your submitted patient list. Picker will follow up on any unresolved queries within two working days. As the survey cannot begin until all samples are approved, if queries are still unresolved after two further working days, NHS England and NHS Improvement will contact the survey lead to offer support in resolving outstanding queries.

Figure 1: Sample Submission and Follow-up Process



Data protection and confidentiality

When carrying out the survey, both Picker and the NHS Trusts will need to ensure they comply with the General Data Protection Regulation 2018 (GDPR) to ensure personal data are kept confidential. The NHS trust will also need to comply with the NHS Code of Practice on Confidentiality (2003), which incorporates the Caldicott Principles.

The guidelines in the Sampling Instructions will help to ensure that data are handled in a manner in keeping with the Data Protection Act 2018, the GDPR, and the Market Research Society's Guidelines for social research (2005). It will be necessary to establish appropriate data security arrangements with Picker, who will send each trust a Data Sharing Agreement governing the transfer of personal data for review and signature (see below for more details).

To find out more information about data protection, please visit the Information Commissioner's Office (ICO) website here: <https://ico.org.uk/>

For further guidance on adhering to the GDPR, see the Market Research Society website here: <https://www.mrs.org.uk/standards/gdprsupport>

Internet transfer of encrypted data

Trusts must send their patient list to Picker over the internet using Picker's secure file transfer website (which uses AES-256 bit SSL encryption). This is to ensure a high level of security and to protect against any accidental or intentional interception during the transfer of patients' details. Picker will provide guidance on the use of an encrypted session to trusts.

Patient lists must not be sent by email: this will be considered a breach of the survey's Section 251 approval. Please refer to the sampling instructions for more detail on the transfer process for the sample data.

The trusts are the owners of the data, so the transfer of patient data is ultimately the trust's decision, because the trust remains legally responsible for the security and processing of the information it shares. Details of using Picker's data transfer system are available in the sampling instructions.

Data Sharing Agreement

A Data Sharing Agreement will be sent digitally to the designated survey lead in each trust and will need to be signed by the trust. By signing this agreement, NHS England and NHS Improvement and Picker, acting under their instructions, are obliged to keep the information received from the trust confidential at all times and to comply with current data protection legislation. It provides the trust with some recourse if a data protection breach were to occur as a result of any actions of Picker. The agreement also ensures that Picker staff members sign and abide by the agreement, which describes how patients' personal data will be sent to Picker, how the data will be stored and how it can be accessed and used.

National Data Guardian Review and patient opt-outs

The Department for Health and Social Care has confirmed that the Under 16 Cancer Patient Experience Survey is exempt from the national data opt-out¹ (National Data Guardian). This exemption will be reviewed after the first two years. Therefore, National Data Guardian opt-outs should not be applied to this survey and you must not exclude patients on this basis. This means that patients do not have to actively consent to their data being used for the purpose of this survey; however as mentioned above, to abide by the survey's section 251

¹ In July 2016 the National Data Guardian (NDG) Review on data security, consent and opt-outs was published. In July 2017 the Department of Health published "Your Data: Better Security, Better Choice, Better Care", the government's response to the NDG review. The review noted that further work was required before a decision could be made as to how the opt-out should be applied to surveys. For more information, please see: <https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document/policy-considerations-for-specific-organisations-or-purposes>

approval, if patients choose to specifically opt-out of the latest survey (e.g. by using the contact details provided on the dissent posters) their wishes should be respected.

Picker is under the obligation to report any breaches to the survey's section 251 approval to NHS England and NHS Improvement and the Confidentiality Advisory Group. Your Trust would also have to review whether the breach needs to be recorded against your Data Security and Protection Toolkit.

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