

# Under 16 Cancer Patient Experience Survey 2021

## Sampling Webinar

12<sup>th</sup> January 2022, 10:00-11:30



**Say hello and introduce yourselves in the chat**



Who are you?

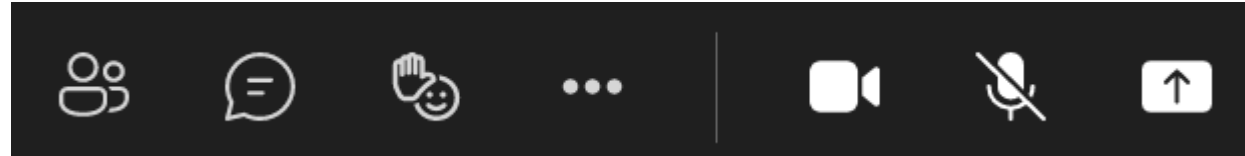
Where are you from?

What is your role?

## U16 Cancer Patient Experience Survey 2021 – Sampling Webinar

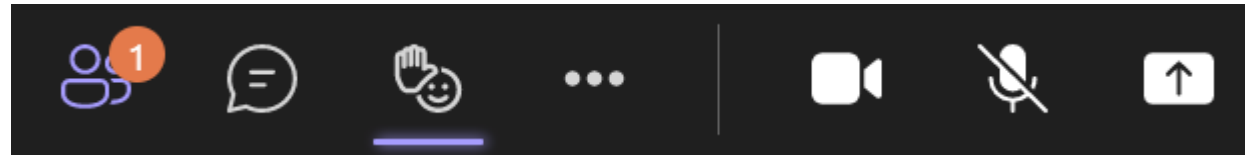
Time	Item
10:00	Introduction and housekeeping
10:10	About the survey
10:20	Compiling your patient sample
10:45	Submitting your patient sample
11:10	Key dates
11:15	Questions

Please



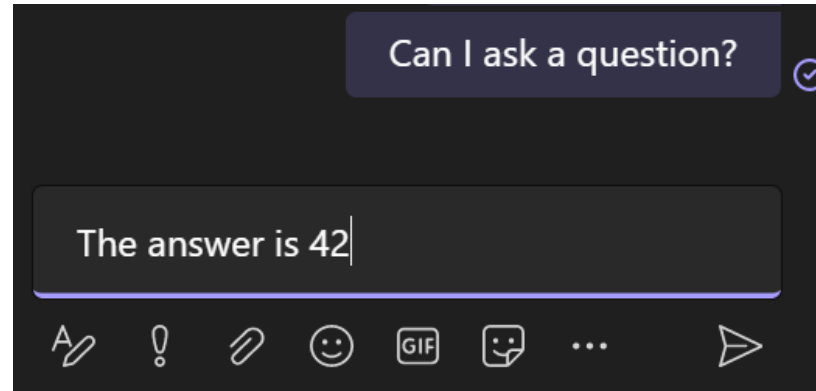
- Keep yourself muted whilst the presentations are ongoing

Please



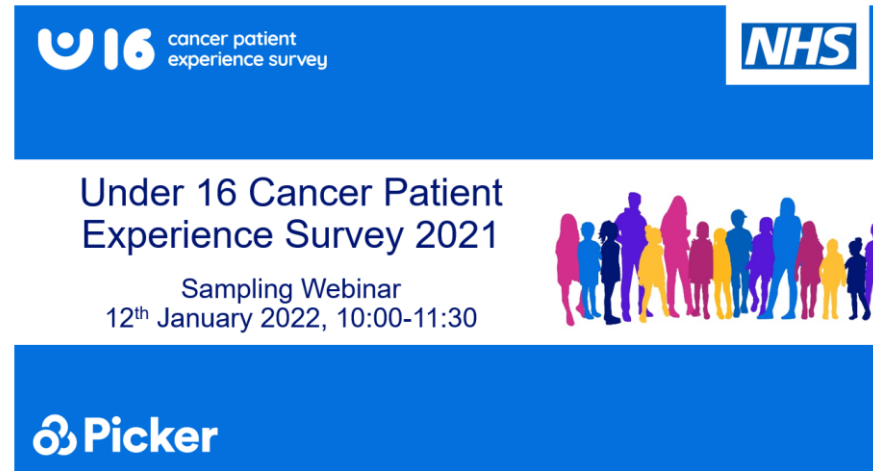
- Keep yourself muted whilst the presentations are ongoing
- Put your hand up if you have a question

Please



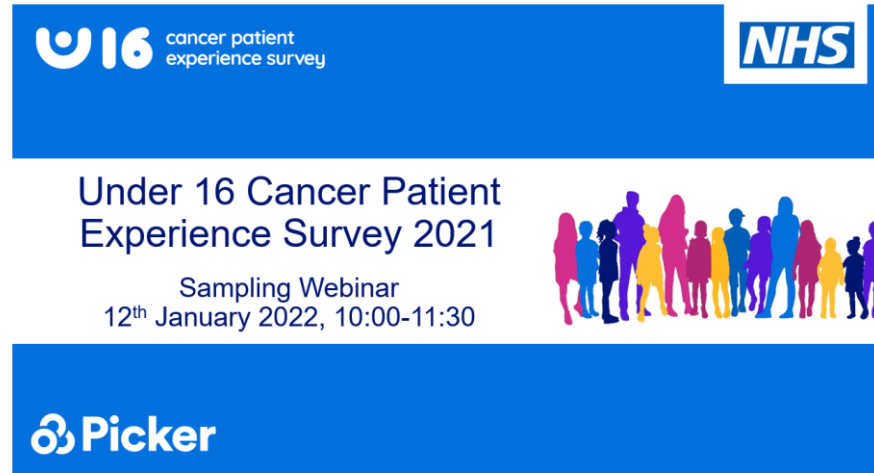
- Keep yourself muted whilst the presentations are ongoing
- Put your hand up if you have a question
- Add your thoughts/questions to the chat

## U16 CPES 2021 Sampling Webinar



- Keep yourself muted whilst the presentations are ongoing
- Put your hand up if you have a question
- Add your thoughts/questions to the chat
- All slides will be circulated after the event

Please,



- Keep yourself muted whilst the presentations are ongoing
- Put your hand up if you have a question
- Add your thoughts/questions to the chat
- All slides will be circulated after the event
- This event is going to be recorded, by remaining you are consenting to being recorded



Say hello and introduce yourselves in the chat



Who are you?

Where are you from?

What is your role?

# About the Survey

Under 16 Cancer Patient Experience Survey



## Under 16 Cancer Patient Experience Survey



- The Under 16 Cancer Patient Experience Survey (U16 CPES) was developed and is implemented by Picker on behalf of NHS England & NHS Improvement.
- **Purpose:** to understand the experiences of cancer care among children under the age of 16 and their parents/carers, in England. Results are used to understand and improve cancer care nationally and locally.
- Supported by a group of expert stakeholders who meet quarterly to advise on methodology.
- Mixed-mode survey (paper and online completion options).
- The survey first ran last year, with results published in October 2021 (see <https://www.under16cancerexperiencesurvey.co.uk/technical-reports>).
- Asks about diagnosis, healthcare staff (e.g. communication, respect and dignity), information about care and treatment, care in hospital, care at home.
- Three survey versions (0-7 years; 8-11 years; 12-15 years).
- Survey website: <https://www.under16cancerexperiencesurvey.co.uk>

# The Questionnaires

## U16 Cancer Patient Experience Survey 2021

**33** When your child was in hospital, were they able to get help from hospital staff when they needed it?

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No



**6** Do you feel that staff are friendly?

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No



**7** When staff speak to you, do you understand what they are saying?

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No
- 4 ☐ Don't know / can't remember

**8** Do staff speak to you in a way that is suitable for you?

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No

**9** Do staff talk to you, not just to your parent or carer?

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No

**10** Do you see the same members of staff for your treatment and care?

- 1 ☐ Yes, always or mostly
- 2 ☐ Yes, sometimes
- 3 ☐ No

**11** Are you ever told different things by different members of staff, which leaves you feeling confused?

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No

**12** Have hospital staff given you information about any of the following people you can chat to about your cancer or tumour? Please select all that apply.

- 1 ☐ Charities (such as Young Lives vs Cancer or Macmillan)
- 2 ☐ A psychologist or counsellor
- 3 ☐ Other children with cancer or a tumour
- 4 ☐ Other
- 5 ☐ No, none of the above
- 6 ☐ Don't know / can't remember

**YOUR CARE AND TREATMENT**

Please answer these questions about the hospital named in the covering letter that came with this questionnaire.

**13** Do you always know what is happening with your cancer or tumour care?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ This is not needed

**14** Do you have a say in deciding what happens with your care?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, sort of
- 3 ☐ No
- 4 ☐ No, but this is not needed or possible

**HOSPITAL WARD**

Please answer the following questions about any hospital ward stays you have had for cancer or tumour care at the hospital named in the covering letter that came with this questionnaire.

**15** Have you visited a hospital ward (receiving treatment or care in the daytime, or for an overnight stay) in the last year?

- 1 ☐ Yes [Go to Question 16](#)
- 2 ☐ No [Go to Question 21](#)

**16** When you were in hospital, were you able to get help from hospital staff when you needed it?

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No

A stylized illustration of a parent and a child sitting on a bench. The parent is on the left, wearing a blue shirt and dark pants, and the child is on the right, wearing a yellow shirt and blue pants. They are both sitting on a blue bench.



The national data opt-out is a service that allows patients to opt out of their confidential patient information being used for research and planning.

The Under 16 Cancer Patient Experience Survey is exempt from the National Data Opt-out Programme, meaning patients are not required to opt-in to taking part. All eligible patients are to be included in the patient list unless otherwise stated, and patients do not have to actively consent to the sharing of their data.

<https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document/policy-considerations-for-specific-organisations-or-purposes>

## U16 Cancer Patient Experience Survey 2021





- The survey has received Section 251 approval from the Research Authority's Confidentiality Advisory Group (**CAG**) and the Secretary of State for Health. This means that the common law duty of confidentiality has been lifted **to allow confidential patient information to be disclosed for the purpose of carrying out the survey.**
- Details on the CAG website: See approved non-research applications register here: <https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/confidentiality-advisory-group-registers/>
- Approval letters also on the U16 CPES website: <https://www.under16cancerexperiencesurvey.co.uk/survey-support-materials>

# Section 251: NHS Trust Requirements

## U16 Cancer Patient Experience Survey 2021



- Trusts must not submit any additional data variables than the ones requested from Picker
- Trusts must ensure they have removed patients that have specifically opted out from this survey via the dissent posters
- Trusts should submit their patient list using Picker's secure site only



### Under 16 Cancer Patient Experience Survey for children, young people and their parents or carers

Help us improve cancer care 

NHS England and NHS Improvement may invite you to take part in the cancer survey for children and young people and their parents and carers. This is part of a national programme to improve care and patients' experiences.

**Your views are important to us**

It is your choice whether to take part in the survey, and your answers will be kept confidential.



If you are invited to take part, the hospital will send your contact details to an independent research organisation, Picker, which is carrying out the survey on behalf of NHS England and NHS Improvement.

If you do not wish to take part, or have any questions about the survey, please contact:

PLEASE INSERT A PHONE NUMBER AND EMAIL ADDRESS OF SOMEONE AT THE HOSPITAL WHO CAN BE CONTACTED TO RECORD DETAILS OF THOSE WISHING TO OPT OUT

Patients opting out please note: by opting out you are removed from the mailing list **for this survey and for this hospital only**, so you might still be included in other surveys. **If you do not wish to receive a survey from another hospital you will need to contact staff at that hospital to opt out.**

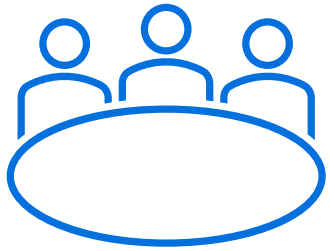
For more information about the survey, please see the survey website:  
<https://www.under16cancerexperiencesurvey.co.uk/>



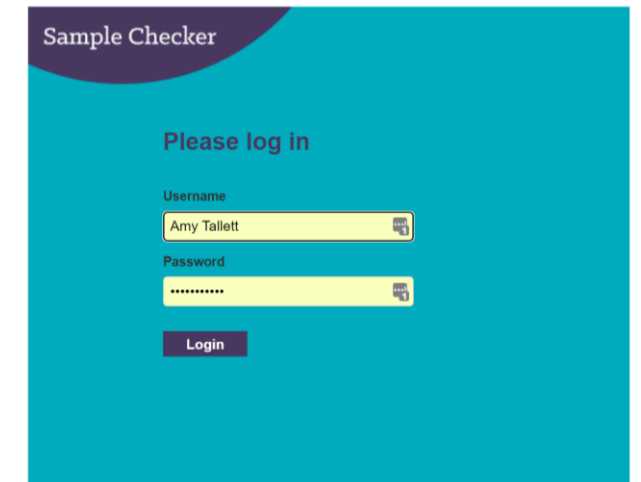


- Keep patient information confidential at all times and to comply with data protection legislation.
- To check for deceased patients before each mailing by submitting the list to DBS and removing patients from any future mailings
- To remove patients that opt out via the Freephone line, email or by returning a blank questionnaire
- To check all free-text comments for any safeguarding concerns and escalate as necessary
- Securely delete patient identifiable information by 12 months after publication of results





- ICD-O3 codes added
  - To improve reporting by diagnostic group
- New secure sample checking platform for uploading patient sample list
  - Log-in details provided after Data Sharing Agreement and Sample Declaration Form have been submitted and checked

A screenshot of a web application titled "Sample Checker". The interface has a teal background. At the top, it says "Sample Checker" in white. Below that, it says "Please log in" in white. There are two input fields: "Username" with the text "Amy Tallett" and "Password" with masked characters "\*\*\*\*\*". Both fields have a small icon on the right. Below the fields is a dark blue "Login" button.

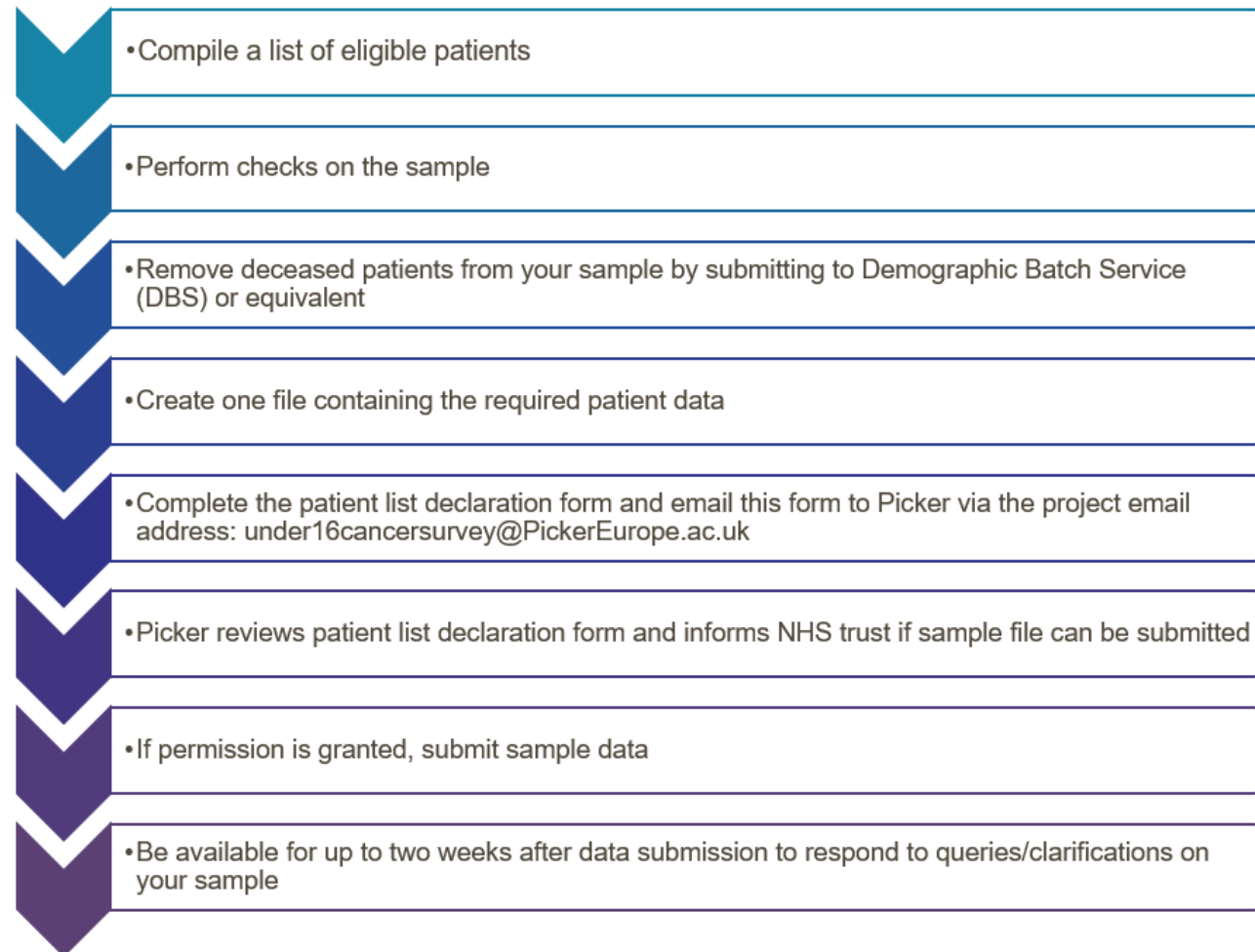
# Compiling your patient sample

Under 16 Cancer Patient Experience Survey 2021



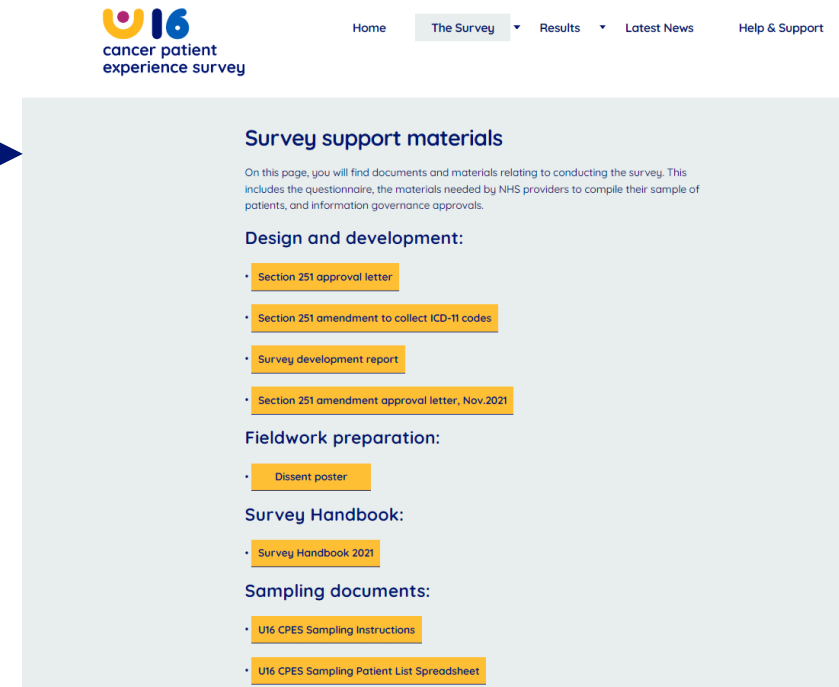
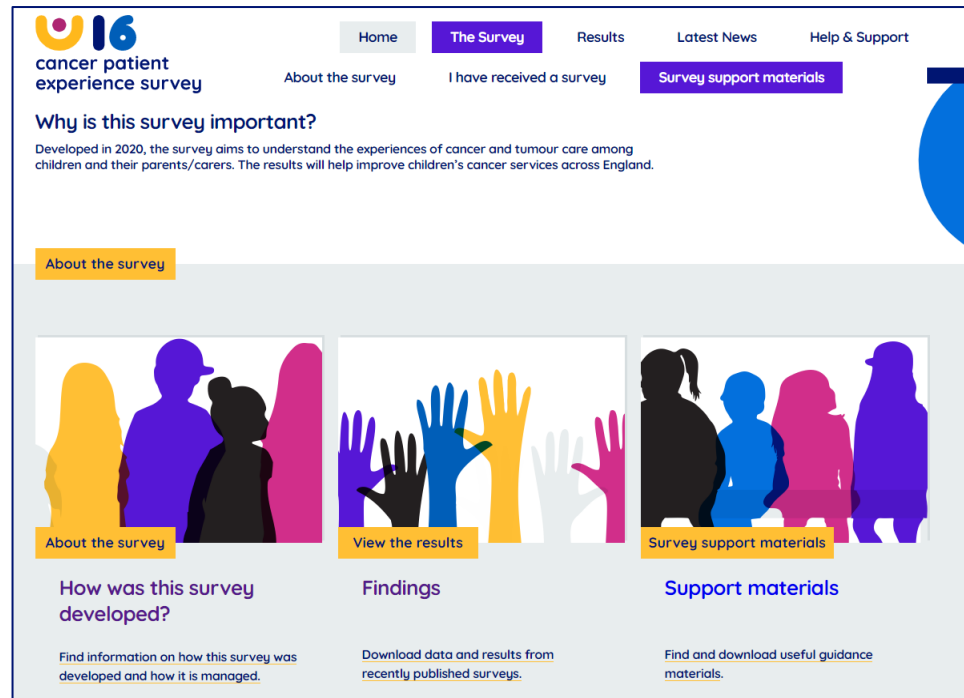
## Under 16 Cancer Patient Experience Survey 2021

The following flowchart shows the sequential steps that you must follow to draw your sample.



## Under 16 Cancer Patient Experience Survey 2021

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



# Sampling Guidance Materials

## Under 16 Cancer Patient Experience Survey 2021

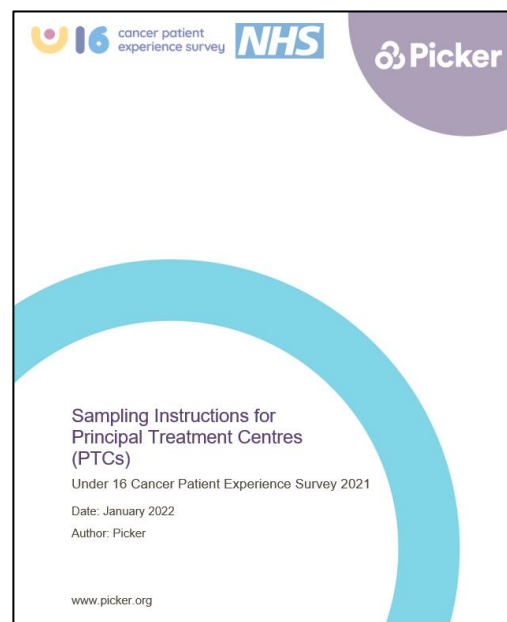
<https://www.under16cancerexperiencesurvey.co.uk/survey-support-materials>

### Sampling Guidance

### Excel template

### Data sharing agreement

### Declaration form



A	B	C	D	E	F
<small>Note: add the NHS number. Instead create a unique code per record, in the format of 'Trust code' (3 characters) plus a unique 4 digit, starting at 1001, e.g. KTH1001. Where there are multiple rows for the same patient, then each row must have a different NHS assigned.</small>					
1	<small>The 3-digit ODS code for your NHS Trust, e.g. 542</small>	<small>The 5-digit ODS code for the NHS site where the patient received care</small>	<small>First name or initials of patient (child)</small>	<small>Last name of patient (child)</small>	<small>First line of address</small>
2	Patient record number (PRN)	NHS Trust Code	NHS Site Code	Patient First Name or Initials	Patient Surname
3					Address 1
4					

**Under 16 Cancer Patient Experience Survey  
Data Sharing Agreement**

THIS AGREEMENT is made and will come into force on **10/01/2022**

**1** Between:  
1) **Name and address (the trust),** and  
2) NHS England and NHS Improvement  
Skipton House  
London  
SE1 6LH

For the purposes of this agreement, Picker Institute Europe is acting as the data processor under the sole instructions of the data controller, NHS England and NHS Improvement.

Picker Institute Europe is a company incorporated and registered in England and Wales under company number 3908160 and a registered charity in England with registered number 1081688 and in Scotland with registered number SC045048 and whose registered office is at Buxton Court, 3 West Way, Oxford OX2 0UB ("Picker").

**2** Definitions See Annex A

**3** BACKGROUND  
The Trust has agreed to provide the data items (listed in 6 of this document) with NHS England and NHS Improvement (for Picker to process) for the purposes of the Under 16 Cancer Patient Experience Survey 2021.

The data items provided to NHS England and NHS Improvement (for Picker to process) shall only be processed in connection with the Under 16 Cancer Patient Experience Survey 2021 and will not be used for any other purposes.

**4** Purpose, objectives of the information sharing:  
The Under 16 Cancer Patient Experience Survey (U16 CPES) is carried out to help the NHS monitor and improve the quality of cancer services so that they better meet patient needs.

**Under 16 National Cancer Patient Experience Survey 2021:  
Sample Declaration Form**

1 This declaration is to be signed off by the member of staff responsible for drawing and checking the patient list, as set out in the Sampling Instructions.

2 This checklist will be used for audit purposes to ensure that the patient list conforms to the instructions. If all steps are completed it will help to avoid any breaches of confidentiality.

3 This survey has received Section 251 approval from the Health Research Authority to enable data to be transferred to Picker for the purposes of this survey only. In order to be operating under that approval, you must follow the steps outlined below, otherwise the approval will not apply. For more information on the approval requirements and confidentiality, please refer to the Survey Handbook.

**How to complete this declaration:**

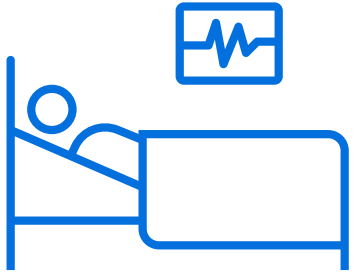
**Checklist:** Please confirm that the checks on the 'Checklist' tab have been completed on behalf of your NHS trust by inserting a '✓' or 'NA' in the boxes adjacent to the check listed.

**Entering an NA:** If an 'NA' is inserted to any of the checks, a comment will be expected from the trust, explaining why this check is not applicable. This will avoid unnecessary queries during the patient list checking process, and help have your patient list approved faster.

**Checks to note:** For rows 31 and 33, a number must be entered instead of a '✓' or 'NA' in the boxes adjacent to the check.

**Declaration agreement:** On the Declaration Agreement tab, enter the required information to confirm that the patient list file has been prepared and is ready to be submitted to Picker for checking. Please wait for a member of Picker staff to tell you when and how you can submit your patient list.

Confirm the following:	Check	Comments
Your patient list consists of eligible patients aged under 16 years with a confirmed primary diagnosis of cancer, and who are aware of their diagnosis, who were admitted as inpatients or seen as day case patients for cancer-related care and have been discharged between January 1, 2021 and December 31, 2021. (Patients who are currently 16 may be included if they were discharged at 15 years old).		
Confirm that you have included:	Check	Comments
Patients with a confirmed primary diagnosis of cancer or one of the specified tumour types. That is, they do not have a holding code and they have been told they have cancer or one of the specified tumour types.		
Patients born in 2005 or after who were aged under 16 at the time they received cancer care (at the time they were discharged as inpatients or day case patients).		
Patients with an ICD-10 code of C00-C97 or D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5, D48, D76.1 (or equivalent ICD-11 code) in the first diagnosis field of their PAS record. Except the exceptions below.		
All eligible patients who had at least one overnight stay or were seen as a day case in which they were receiving cancer-related care or treatment.		
Patients whose address is incomplete, but contains enough information to have a reasonable chance of being delivered. E.g. Keep in those with address 1 and post code; complete address without a post code; address without city or county details but with post code.		
Patients with an address in the UK including addresses in the British Islands (Isle of Man, the Channel Islands) and addresses for a military base, care home or prison establishment.		
Duplicate patients (i.e. the same patient that has multiple care episodes should be included in multiple rows).		
Confirm that you have excluded:	Check	Comments
Patients aged 16 years and older at the time they received cancer care (either at the time they were discharged, inpatients and day case patients).		
Patients without a confirmed diagnosis of cancer or one of the specified tumour types.		

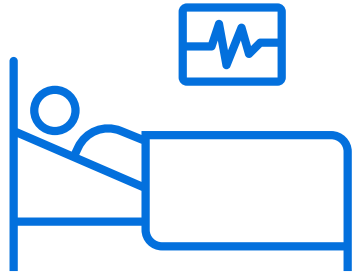


## INCLUDE:

- All children aged under 16 at the time of their care who have been discharged for cancer related care or treatment between January 1, 2021 and December 31, 2021.
- With a confirmed primary diagnosis of cancer or a non-malignant brain, other central nervous system or intracranial tumour.
  - ‘Primary cancer’ is defined as the main diagnosis shown on your system, regardless of how many times someone has had cancer in the past or how progressive their cancer is.
- Inpatients and day case admissions who have received NHS care and/or treatment (elective and non-elective) in England for their cancer or tumour.

## U16 Cancer Patient Experience Survey 2021

### INCLUDE:



- All children aged under 16 at the time of their care who have been discharged for cancer related care or treatment between January 1, 2021 and December 31, 2021

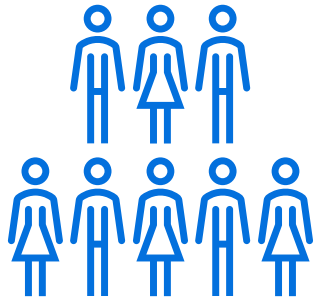
- With a confirmed diagnosis of cancer, including brain, other

- 'Primary diagnosis' system, past or present

- Inpatients at the time of their care and/or at the time of their cancer diagnosis

- **Day** of the month of discharge (1 or 2 digits; e.g. 2 or 30)
- **Month** of discharge (1 or 2 digits; e.g. 4 or 5)
- **Year** of discharge (4 digits; e.g. 2021)
- **ICD10 Code** – 4 digits, including sub-categories for these codes, i.e. C25.1.
  - These must be coded in the **primary diagnosis field** and should be between C00 & C97 and D codes, of: D32 - D33, D35.2 - D35.4, D42 - D43, D44.3 - D44.5, D48, D76.1
  - *Please note that if you provide the ICD10 Code, you do not need to provide the ICD11 Code.*
- **ICD11 Code** – These must be coded in the **primary diagnosis field** and should match the codes provided in Appendix B.
  - *Please note that if you provide the ICD11 Code, you do not need to provide the ICD10 Code.*
- **ICD-O-3 site code** (4 digits)<sup>3</sup> as per the validation list available here: <https://seer.cancer.gov/icd-o-3/>, e.g. C488

## Please ensure that:



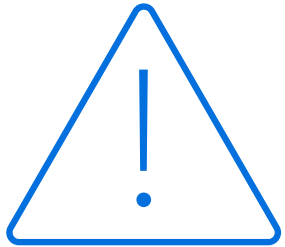
- Only patients that are seen by the cancer teams are included in the sample
  - Some patients may have been seen by non-cancer teams, such as epilepsy surgery or rheumatology patients with macrophage activation syndrome
- Patients are aware of their diagnosis
  - Will likely require a cancer team member checking the patient list
- Duplicate patients are **not** removed
  - Patient list must include all eligible instances of care, so some patients may appear more than once
- Parent mobile phone number and email address are included





## EXCLUDE:

- Deceased patients
- Outpatients
- Patients without a confirmed diagnosis of cancer or one of the specified tumours, including those given a holding diagnosis code with pending results
- Patients who are not aware of their diagnosis of cancer or one of the specified tumours (this will require a check by a member of your clinical cancer team)
- Patients aged 16 years and older at the time they were discharged from inpatient or day case care
- Private patients (non-NHS)
- Patients without a UK postal address (but do not exclude if addresses are incomplete but useable, e.g. no post code)
- Parents/patients that have informed your trust, in response to communications about the Under 16 Cancer Patient Experience Survey, that they (or their child) do not wish to be included in the survey.

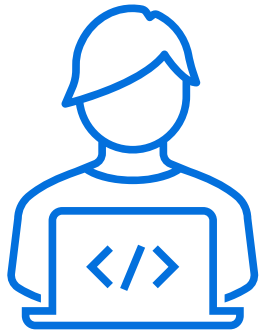


- Only include patients discharged during the sampling frame (1<sup>st</sup> January – 31<sup>st</sup> December 2021)
- Ensure that emergency admissions are included
- Do **not** remove duplicates – so in many instances, a patient will appear multiple times in your sample (one row/record per discharge)
- Include *all* eligible patients, not just those who are newly diagnosed

# Submitting your patient sample

Under 16 Cancer Patient Experience Survey 2021





- Make sure you have the relevant permissions to share the data by completing and submitting the **Data Sharing Agreement** to [under16cancersurvey@PickerEurope.ac.uk](mailto:under16cancersurvey@PickerEurope.ac.uk)
- When your sample list is ready, please complete the **Patient List Declaration Form** (to confirm the sample has been drawn following the guidance with the necessary checks), and email to [under16cancersurvey@PickerEurope.ac.uk](mailto:under16cancersurvey@PickerEurope.ac.uk)
- Once your forms have been received and checked, you will be emailed details of how to access Picker's online sample checker platform <https://samplechecker.picker.org/>

# How to submit your patient sample

## U16 Cancer Patient Experience Survey 2021

<https://samplechecker.picker.org/>



Home

Guide & FAQs

Contact us

Welcome Test from Test org

**To upload a file for a survey, please select the appropriate survey from the list below**

To upload a file into the platform, please first populate the appropriate template. These templates are available for download below.

If the survey you need is not listed, please contact [clientservice@pickereurope.ac.uk](mailto:clientservice@pickereurope.ac.uk)




U16 CPES Survey

**Download the data template for submission**


# How to submit your patient sample

## U16 Cancer Patient Experience Survey 2021

<https://samplechecker.picker.org/>










**In progress files that have been uploaded are within the table below**  
To continue working on a file, please select the 'View upload details' button  under the Actions column for the appropriate upload.  
Found 1 previously uploaded sample file.

Show  entries Search:

Survey code	Status	# records	# queries	Last modified	Actions
UEC20	Upload has queries	3550	Errors 10 Checks 5 Notices 0 Historic 7 Total open queries 22	2020-10-01 10:11:00	

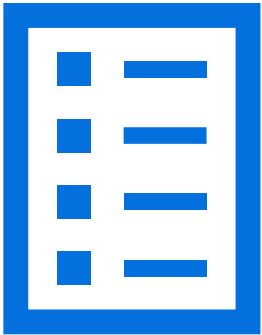
Showing 1 to 1 of 1 entries Previous  Next

Show  entries Search:

Status	Type	Data field	# Issues	Explanation	Details
Trust	Error	Organisation Name - Organisation code doesn't match expected code ASD	3975		
Trust	Error	Ethnicity - Invalid value(s) found. Valid values are single letters.	2		
Trust	Error	Maternity - Invalid value(s) found. Valid values are 0 or 1.	3975		
Trust	Check	Ethnicity - Information only - Extended ethnicity code(s) / description(s) found. Automatically adjusted to first letter ethnicity code(s).	3920		
Trust	Check	Job Title - Please confirm that these staff have a substantive role and are on the organisation's payroll.	3		
Trust	Check	Job Title - Please confirm that these staff either were a Student Nurse and on the organisation's payroll as of the 1st September OR are NOT a student Nurse AND have a substantive role and are on the organisation's payroll.	1		
Trust	Error	Post room - Record(s) with an 'Paper' 'Survey Mode', but do not have a post room listed. Paper surveys can only be delivered when post rooms are provided (home address should have this populated with 'Z/DEFAULT HOME').	122		
Trust	Check	Maternity - No values of 1 found. Please confirm that there are no staff currently on parental leave.	1		
Trust	Check	Locality - Locality 1: (Blank) - 2 has fewer than 11 records. Please revise in line with your organisation's reporting needs, or these will be automatically grouped together as an 'Other' locality group. Please confirm if you wish to proceed.	1		

### TYPES OF QUERY:

- **Error** – to resolve these issues you will need to upload a revised sample file
- **Check** – queries that may or may not be an error, to resolve you will need to provide an explanation or upload a revised file
- **Historical difference** – indicates a >5% difference in the sample file compared to the previous year. If >5% difference, please provide confirmation that this has been checked
- **Notice** – provides an overview of the information in the sample, no action needed



- Picker will share mailing dates with Trusts once they are confirmed
- Picker will conduct DBS checks within 24 hours prior to each survey mailing
- If Trusts wish to do a local check before each mailing, this is most welcomed
- If a Trust needs to inform Picker of a deceased patient, they will need to contact Picker with the unique Patient Record Number(s) so we can ensure they are removed from the mailing. This will need to be **at least 48 hours before the mailing date.**



# Key sampling dates

Under 16 Cancer Patient Experience Survey 2021



## U16 Cancer Patient Experience Survey 2021

Dates	Task	Responsibility (Trusts/ Picker)
Mid Dec 2021	Sampling instructions available to Trusts	Picker
12th Jan 2022 10-11:30am	Webinar to discuss sampling with Trusts	Picker
w/c 17 <sup>th</sup> Jan 2022	Patient list submission start date – for Trusts to aim towards for submitting their sample (Trusts can submit earlier than this if their list is ready and forms are sent).	Trusts
4 <sup>th</sup> Feb 2022	Last date for Data Sharing Agreement, Patient Declaration Form and Patient Sample (with deceased patients removed) to be submitted to Picker.	Trusts
17 <sup>th</sup> Jan - 4 <sup>th</sup> Mar 2022	Picker to check samples. Trusts to respond to queries	Picker & Trusts
18 <sup>th</sup> Feb 2022	Final date patient samples can be approved for inclusion in the survey	Picker & Trusts
4 <sup>th</sup> March 2022*	Patient list finalised	Picker
31 <sup>st</sup> March 2022*	Picker to conduct DBS trace and send the first survey invite	Picker
21 <sup>st</sup> April 2022*	Picker to conduct DBS trace and send the first reminder	Picker
12 <sup>th</sup> May 2022*	Picker to conduct DBS trace and send the final reminder	Picker
June 2022	Fieldwork closes	Picker
Jun/July 2022	Analysis and reporting begins	Picker

*\* These are estimated dates – final dates will depend on the timely submission of patient samples and resolution of queries across all Trusts*

# Sampling Questions

Under 16 Cancer Patient Experience Survey 2021





### **Within the sampling period, a patient might turn 16. Should they still be included?**

- Yes – any episodes of cancer-related care and treatment that the patient received when they were under 16, during the defined sampling period of 1<sup>st</sup> Jan and 31<sup>st</sup> Dec 2021, should be included. If they turn 16 in July for example, only those episodes of care received between January and July should be included.

### **Do all the radiotherapy sessions have to be counted as day cases or do we count them as a whole treatment?**

- Yes, the sampling process would consider each radiotherapy session an individual care episode and each eligible instance to be included in your sample, after which Picker would remove duplicate patient records. However, if this will result in a significant amount of work to re-code your patient lists, please speak to Picker in the first instance as we do not want to place unnecessary burden on trusts.

### **We don't record parent mobile phone or email data, is this a problem?**

- We are aware of potential variation in the availability of this data and how it is recorded/accessed. The collection of parent email and phone data is to explore whether this data can be used for alternative methods in future survey waves, so it is important to include where available.

## U16 Cancer Patient Experience Survey 2021



**Looking into the necessity of patients to be informed of their cancer diagnosis, is it ok if only the parents know that the child has cancer?**

- Yes. The mailing is sent to the parent/carer of the child, and the parent/carer will therefore be the first to open the envelope and read the survey invite letter. It is then up to the parent to decide whether to share the survey invitation with their child which may depend on various factors such as whether they consent to their child taking part, whether their child is aware of their diagnosis, and their child's current health status.

**Some people receive care which is not directly cancer-related but for symptoms relating to side effects of treatment. We log these instances as supportive care. Would these instances be included in the sample?**

- As long as supportive care is provided directly by members of the cancer team, it should be included in the sample. If this care is not provided by the cancer team, then please exclude these instances.

## U16 Cancer Patient Experience Survey 2021



### What opt-out options will patients have?

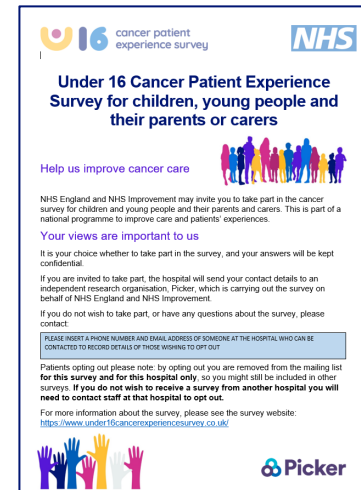
- If your trust has advertised the survey through the dissent poster provided, patients may have contacted your trust to opt out from taking part. If they did, these patients should be recorded and removed from your patient list before submitting to Picker.
- Patients can also opt out by calling the Freephone line or helpline email provided on the questionnaire and covering letters, or by sending back a blank questionnaire.

### When patients appear on more than one trusts list, how will you choose which trust the patient is asked about on the questionnaire?

- The trust that was attended most frequently during the sample period will be asked about.

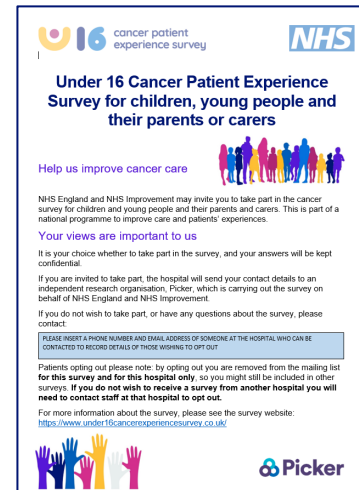
### When patients appear multiple times on a trust list, how will you choose which record to retain?

- The one with the latest discharge date. However, the questionnaire will ask patients to feedback on care during the whole of 2021.





**Questions from today's webinar  
will be uploaded here shortly.**



# Contact Details and Support

Under 16 Cancer Patient Experience Survey 2021





## Contact Details

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## Key Contact Details

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