

# Under 16 Cancer Patient Experience Survey - 2020

Sampling Webinar

January 2021

# Agenda



- Housekeeping
- Background
- Guidance materials
- Sampling criteria
- Sample fields
- Process for compiling, checking and submitting your sample
- Key dates
- Your role / Picker's role
- Questions

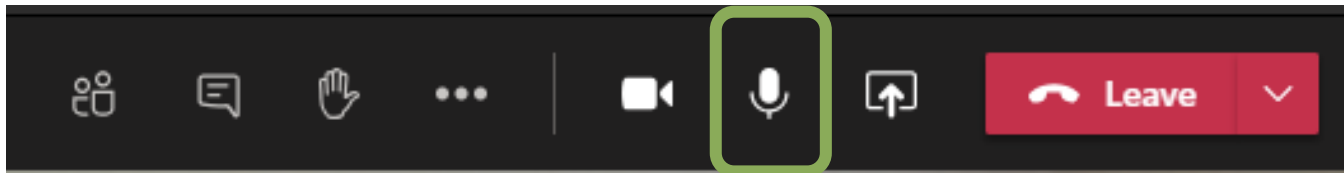
# Housekeeping: Audio Settings



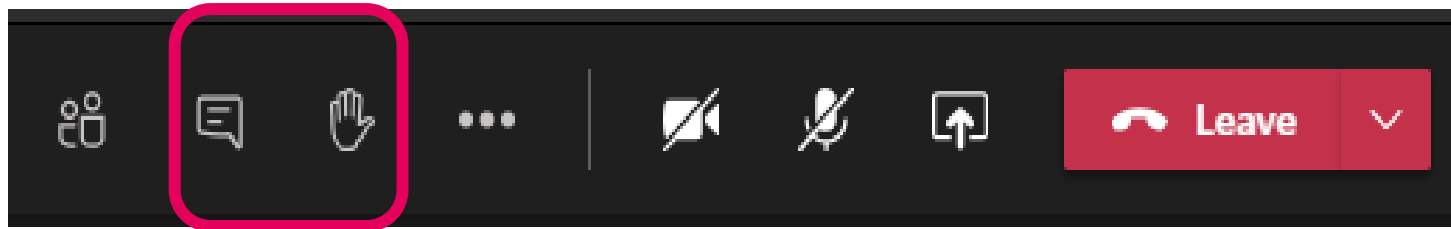
- Muted



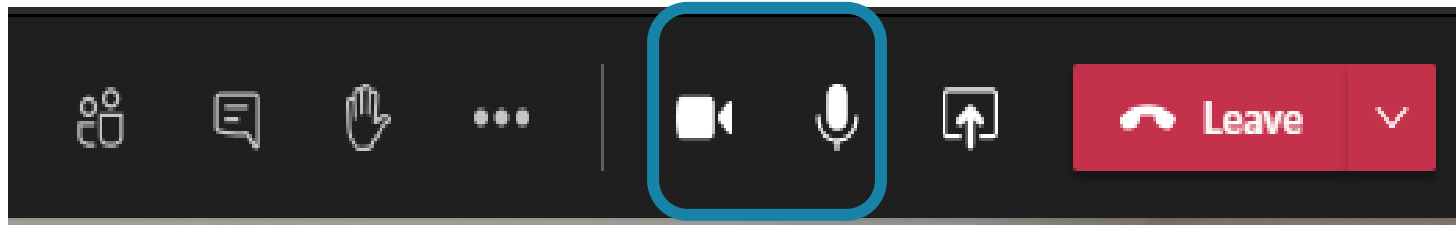
- Unmuted



# Housekeeping: Questions



# Housekeeping: Participation



# Housekeeping: Manage your bandwidth



# Background

# The Under 16 Cancer Patient Experience Survey - Background

- Developed and 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 will be used to understand and improve cancer care nationally and locally.





# Under 16 Cancer Patient Experience Survey

## Survey Type

0-7 year olds:  
parents/carers only

8-11 year olds: children  
and parents/carers

12-15 year olds: children  
and parents/carers

## Sections

Finding out about your cancer or tumour

Healthcare staff

Your care and treatment

Hospital ward

Care at home

Overall

About you

Anything else to say?

# Questionnaires



## HEALTHCARE STAFF

Please answer the following questions about any healthcare staff you have seen for your child's cancer or tumour in the last year, hospital named in the covering letter.

4. Was your child told they had cancer or a tumour at the hospital named in the letter that came with this questionnaire?  
☐ Yes Go to Question 5  
☐ No Go to Question 10

5. How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?  
☐ I was seen as soon as I thought was necessary  
☐ I should have been seen a bit sooner  
☐ I should have been seen a lot sooner

6. Were you told about your child's cancer or tumour in a sensitive way?  
☐ Yes, definitely  
☐ Yes, to some extent  
☐ No  
☐ Don't know / can't remember

7. When you were told about your child's cancer or tumour, was information given in a way that you could understand?  
☐ Yes, definitely  
☐ Yes, to some extent  
☐ No  
☐ Don't know / can't remember

8. Were you able to have any questions answered by healthcare staff after you were told about your child's cancer or tumour?  
☐ Yes, definitely  
☐ Yes, to some extent  
☐ No  
☐ I didn't have any questions  
☐ Don't know / can't remember

9. Have you been able to find the information that you need about your child's diagnosis?  
☐ Yes, definitely  
☐ Yes, to some extent  
☐ No  
☐ This was not needed

## NHS Under 16 Cancer Patient Experience CHILDREN'S SECTION

These questions are about the care you received. For each question please cross X clearly inside one box using the survey website [www.under16cancerpatientexperience.nhs.uk](http://www.under16cancerpatientexperience.nhs.uk). Your answers will help to make children's cancer and tumour care better. We will make sure that nobody can tell which answers are yours. You're the expert in what your care is like, so please answer the questions.

### FINDING OUT ABOUT YOUR CANCER OR TUMOUR

If you have had cancer or a tumour more than once, please think about the most recent time when answering the following questions.

1. Were you told you had cancer or a tumour within the last year?  
☐ Yes Go to Question 2  
☐ No Go to Question 6

2. Were you told you had cancer or a tumour at the hospital named in the letter that came with this questionnaire?  
☐ Yes Go to Question 3  
☐ No Go to Question 6

3. When you were told about your cancer or tumour, was information given in a way that you could understand?  
☐ Yes, definitely  
☐ Yes, sort of  
☐ No  
☐ Don't know / can't remember

### HEALTHCARE STAFF

Please answer the following questions about any healthcare staff you have seen for your cancer or tumour in the last year, hospital named in the letter that came with this questionnaire.

4. Were you able to have any questions answered by healthcare staff after you were told about your cancer or tumour?  
☐ Yes, definitely  
☐ Yes, to some extent  
☐ No  
☐ I didn't have any questions  
☐ Don't know / can't remember

5. Did hospital staff contact you if you were told about your cancer or tumour?  
☐ Yes  
☐ No  
☐ Don't know

6. Do you feel that staff were helpful?  
☐ Yes, always  
☐ Yes, sometimes  
☐ No

## CARE AT HOME

Have you been visited at home by a nurse in the last year, for care for your cancer or tumour?  
☐ Yes Go to Question 24  
☐ No Go to Question 27  
☐ Don't know / can't remember Go to Question 27

16. When you were in hospital, were you able to get help from hospital staff when you needed it?  
☐ Yes, always  
☐ Yes, sometimes  
☐ No

17. Were there enough things for you to do in the hospital?  
☐ Yes, definitely  
☐ Yes, sort of  
☐ No  
☐ This was not needed

18. Was there a choice of hospital food?  
☐ Yes, definitely  
☐ Yes, sort of  
☐ No  
☐ I did not have hospital food

19. Were you given somewhere private to talk to staff when you were in hospital?  
☐ Yes, always  
☐ Yes, sometimes  
☐ No  
☐ This was not needed

20. Was it quiet enough for you to sleep in the hospital?  
☐ Yes, always  
☐ Yes, sometimes  
☐ No  
☐ I did not need to sleep in the hospital

21. Were the nurses that came to your home friendly?  
☐ Yes, always  
☐ Yes, sometimes  
☐ No  
☐ Don't know / can't remember

22. When nurses speak to you, do you understand what they are saying?  
☐ Yes, always  
☐ Yes, sometimes  
☐ No  
☐ Don't know / can't remember

23. Did the same nurses come to your home?  
☐ Yes, always  
☐ Yes, sometimes  
☐ No  
☐ I have only been visited once

## OVERALL

24. Overall, how well are you looked after for your cancer or tumour by the healthcare staff?  
☐ Very well  
☐ Quite well  
☐ OK  
☐ Not very well  
☐ Not at all well

25. Do different hospitals providing your cancer or tumour care work well together?  
☐ Yes, definitely  
☐ Yes, to some extent  
☐ No  
☐ I don't receive care at different hospitals

# National data opt-out programme

The Under 16 Cancer Patient Experience Survey has been 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.

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

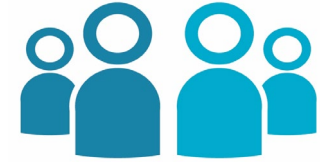
# Section 251 requirements



The survey has received Section 251 approval from the Health 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/>

# Picker project team



## Central Team:

- Amy Tallett, Head of Research
- Megan Bilas, National Programme Lead
- Juan Abad-Madroño, Research Associate

## Project Administrators:

Lacey Walton

Melissa Butcher

### **Key contact details**

[under16cancersurvey@PickerEurope.ac.uk](mailto:under16cancersurvey@PickerEurope.ac.uk)

Megan Bilas: 01865 208121

Juan Abad-Madroño: 07557 965833

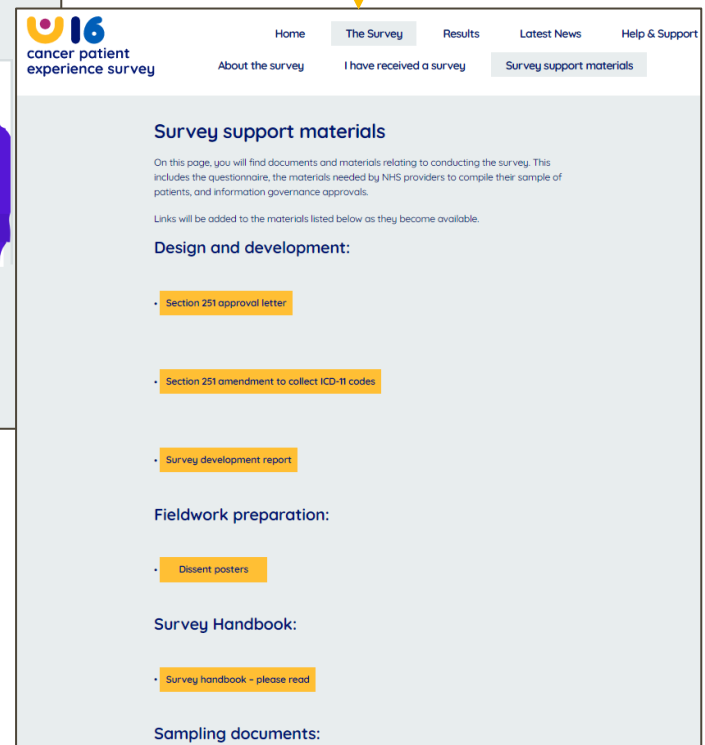
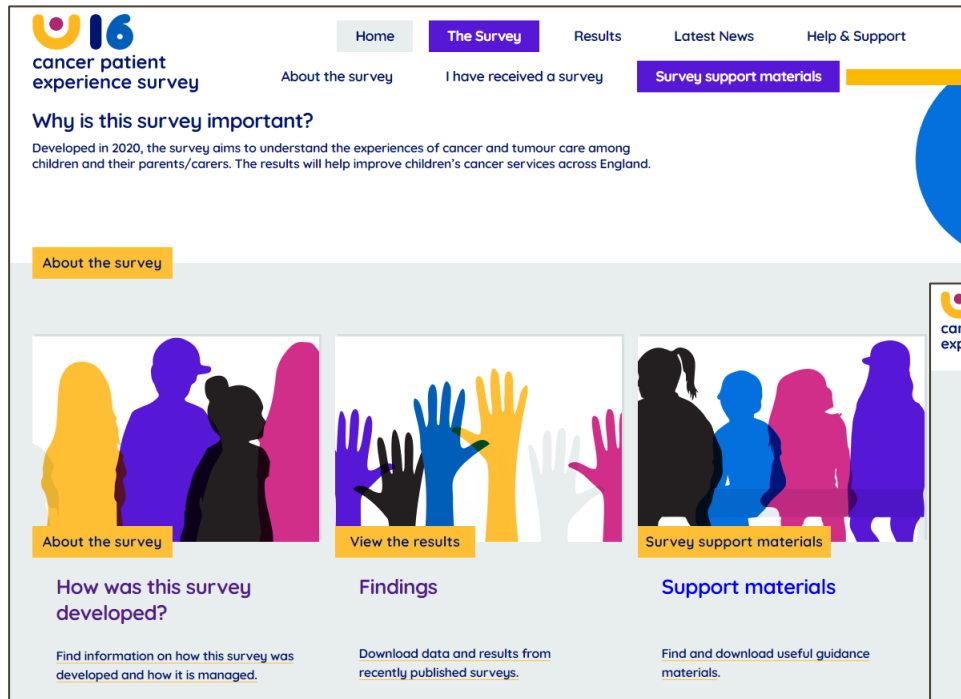
# Guidance materials

# Sampling Guidance Materials



- On the website:  
(<https://www.under16cancerexperiencesurvey.co.uk>)
  - Survey handbook
  - Sampling instructions
  - Webinar slides
- Emailed (can also be re-sent by contacting [under16cancersurvey@pickereurope.ac.uk](mailto:under16cancersurvey@pickereurope.ac.uk)):
  - Patient list construction spreadsheet
  - Sample declaration form
- To be sent to each Trust, individually:
  - Instructions on how to log-in and use the Picker FTP

# [under16cancerexperiencesurvey.co.uk/ survey-support-materials](https://under16cancerexperiencesurvey.co.uk/survey-support-materials)





# Sampling criteria

# Include all children aged under 16 at the time of their care...



- Who have been discharged as inpatients or as day case patients for cancer related care or treatment between January 1, 2020 and December 31, 2020
- With a confirmed primary diagnosis of cancer, who are aware of their diagnosis (specified by ICD-10 code of C00-C97)

**OR**

- With a confirmed primary diagnosis of a non-malignant brain, other central nervous system or intracranial tumour (specified by an ICD-10 code of: D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5, D48, D76.1)

# Important!



- **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
- **Do not remove duplicate patients**
  - Patient list must include all eligible instances of care, so some patients may appear more than once

# Exclude...



- Deceased patients
- Patients without a confirmed diagnosis of cancer or one of the specified tumours, including patients who have been 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

# Exclude...



- 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.

# Sample fields

# Trust/site fields



- NHS Trust Code
- NHS Hospital Site Code

# Name/address fields



- Patient (child) First name or initials
- Patient (child) Surname
- Address Fields
- Post code

# NHS number/PRN fields



- NHS Number
- Patient Record Number (PRN)

# Date fields



- **Day** of birth / **Month** of birth / **Year** of birth
- **Day** of discharge / **Month** of discharge / **Year** of discharge

# Demographic fields



- Gender
- Ethnicity



# Medical fields



- **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 A.
  - Please note that if you provide the ICD11 Code, you do not need to provide the ICD10 Code.
- **Main Specialty on discharge**
- **Patient classification**

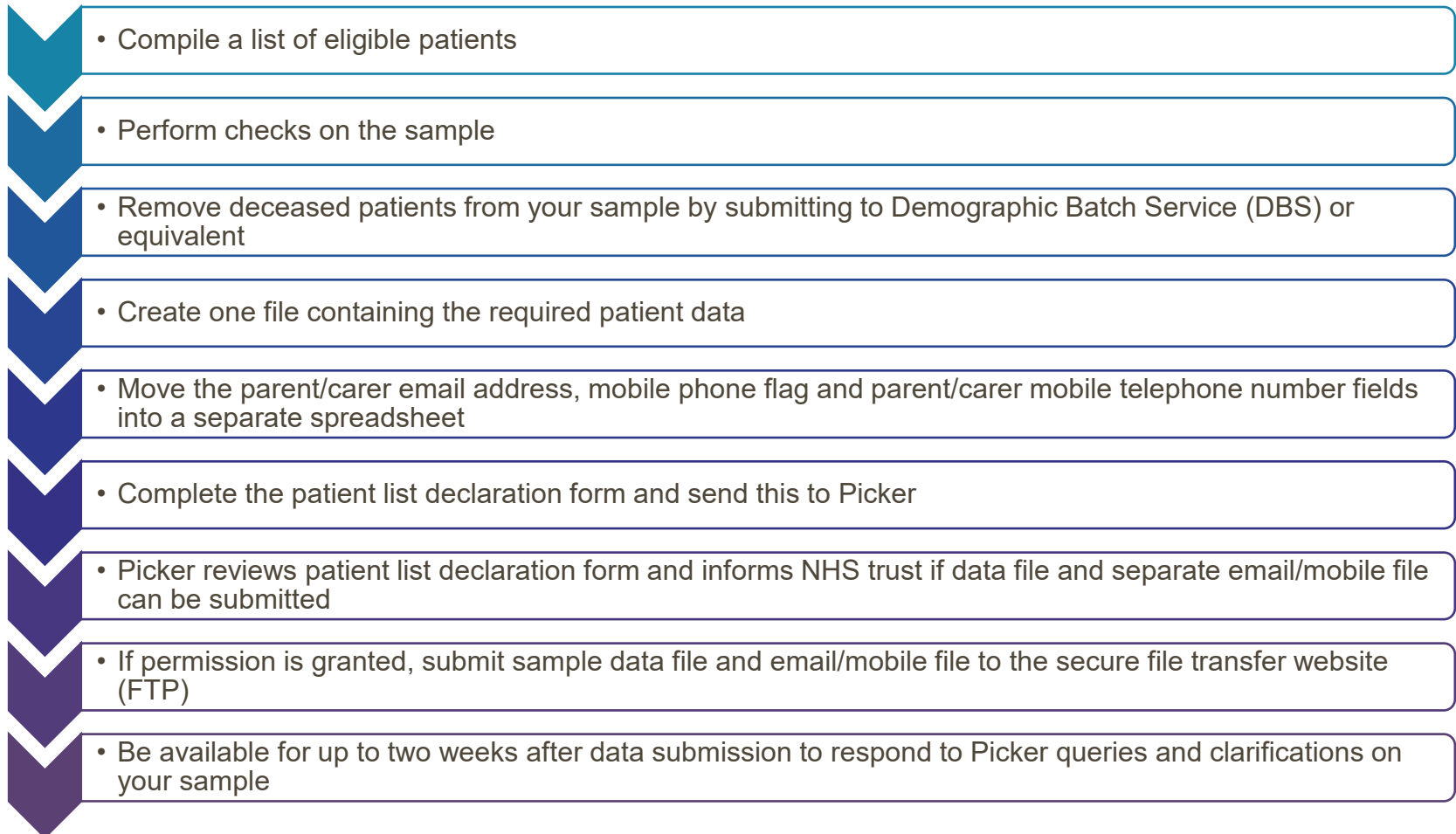
# Email/mobile fields



- **Parent/carer email address** if available. Please check that this belongs to the parent/carer, not the child/patient.
- **Mobile phone number flag** – this will be used to indicate if any mobile phone number is associated with the record. Code as 1=parent/carer mobile available, 2=child mobile available, 3=mobile available but don't know who this belongs to, 0=no mobile available.
- **Parent/carer mobile phone number** if available. Please check that this is the mobile telephone number, not the landline number and that this belongs to the parent/carer. If the number belongs to a child or if it is unclear who the number belongs to, leave this field blank

# Process for compiling, checking and submitting your sample

# Sampling Flowchart



# Step 1: Compile list of eligible patients, using construction spreadsheet

Day of birth	Month of birth	Year of birth	NHS number	Gender	Ethnicity
Day of birth (1 or 2 digits; e.g. 7 or 26)	Month of birth (1 or 2 digits) 1=Jan; 2=Feb; 3=Mar; 4=April; 5=May; 6=June; 7=July; 8=Aug; 9=Sept; 10=Oct; 11=Nov; 12=Dec	Year of birth: 4 digits; e.g. 2019	A 10 digit number. Required for DBS checks	1:=male; 2=female; 0=not known; 9=not specified	1 letter. Ethnic category (N) A=White British B=White Irish C=White other D=Mixed white and black Caribbean E=Mixed white and black African F=Mixed White and Asian G=Mixed other H=Asian Indian J= Asian Pakistani K=Asian Bangladeshi L=Asian other M=Black Caribbean N=Black African P=Black other R=Chinese S=Any other ethnic group Z=Not stated
1	1	2006	1111111111	male	A
2	1	2012	2222222222		2 D
32	1	2002	3333333333		1 R
3	1	2021			0 I

## Step 2 and 3: Perform checks on the sample and remove deceased patients



- Check again that you have correctly followed the points outlines in the sampling instructions and survey handbook
- Make sure that a member of your clinical cancer team checks the patient list
- Make sure that none of the fields in the construction sheet are red
- Removed deceased patients

# Steps 4 and 5: Create two separate files

- Main patient list should include all fields in the construction spreadsheet, **EXCEPT FOR**
  - Parent/carer email address
  - Mobile phone number flag
  - Parent/carer mobile phone number
  - This should be saved as  
NHSTrustName\_U16Cancerwave1.xls

# Steps 4 and 5: Create two separate files

- Email/phone list should **INCLUDE**
  - NHS Trust Code
  - NHS Site Code
  - Parent/carer email address (if available)
  - Mobile phone number flag
  - Parent/carer mobile phone number (if available)
  - This should be saved as  
NHSTrustName\_U16Cancerwave1\_EmailPhone.xls



# Step 6: Complete the declaration form and send this to Picker

- Requirement of the survey's Section 251 approval
- Picker will check the form and provide confirmation if the trust can securely upload their file.
  - Picker will provide instructions on how to upload the data via their secure file transfer site. **Please do not send the patient list using any other method. Patient lists should NEVER be sent by email.**
- If the Patient List Declaration Form is not received or if there is a need to query anything relating to the form, this can delay the sample upload and checking process.

# Step 6: Declaration form

## Under 16 National Cancer Patient Experience Survey: Sample Declaration Form



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.

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.

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.

# Step 6: Declaration form

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, 2020 and December 31, 2020. (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 <b>confirmed primary diagnosis of cancer or one of the specified tumour types</b> . 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 2004 or after who were <b>aged under 16 at the time they they received cancer care</b> (at the time they were discharged as inpatients or day case patients).	✓	
Patients with an ICD-10 code of <b>C00-C97 or D32 - D33, D35.2 - D35.4, D42 - D43, D44.3 - D44.5, D48, D76.1</b> (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 <b>receiving a cancer-related care</b>		
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.	✓	PRN RTH1001 does not have a postcode available but there are full address details.
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 have not been removed and are all included in the patient list.	✓	

# Step 6: Declaration form

Declaration by trust staff compiling the patient list	
<p>I understand that any errors with the way the patient list has been compiled may limit, or prevent, the use of the survey data. Where data cannot be used, this would mean survey results would not be available for my trust in 2020.</p>	
<p>I confirm that the steps outlined within the <i>Checklist</i> tab have been completed and that the patient list has been compiled in accordance with the Survey Instructions.</p>	
<p>I will be required to amend or update the patient list if any errors or deviations are identified during the checks conducted by Picker.</p>	
<p>I confirm that if I am unavailable or unable to submit the patient list or to respond promptly to Picker queries regarding the patient list, someone from the trust will be allocated to cover this task in my absence.</p>	
Trust name	
Contact name	
Contact email address	
Contact phone number	
Date sample signed off by sample drawer	
<b>ATTENTION! You have not completed all the fields in the 'Checklist' tab</b>	

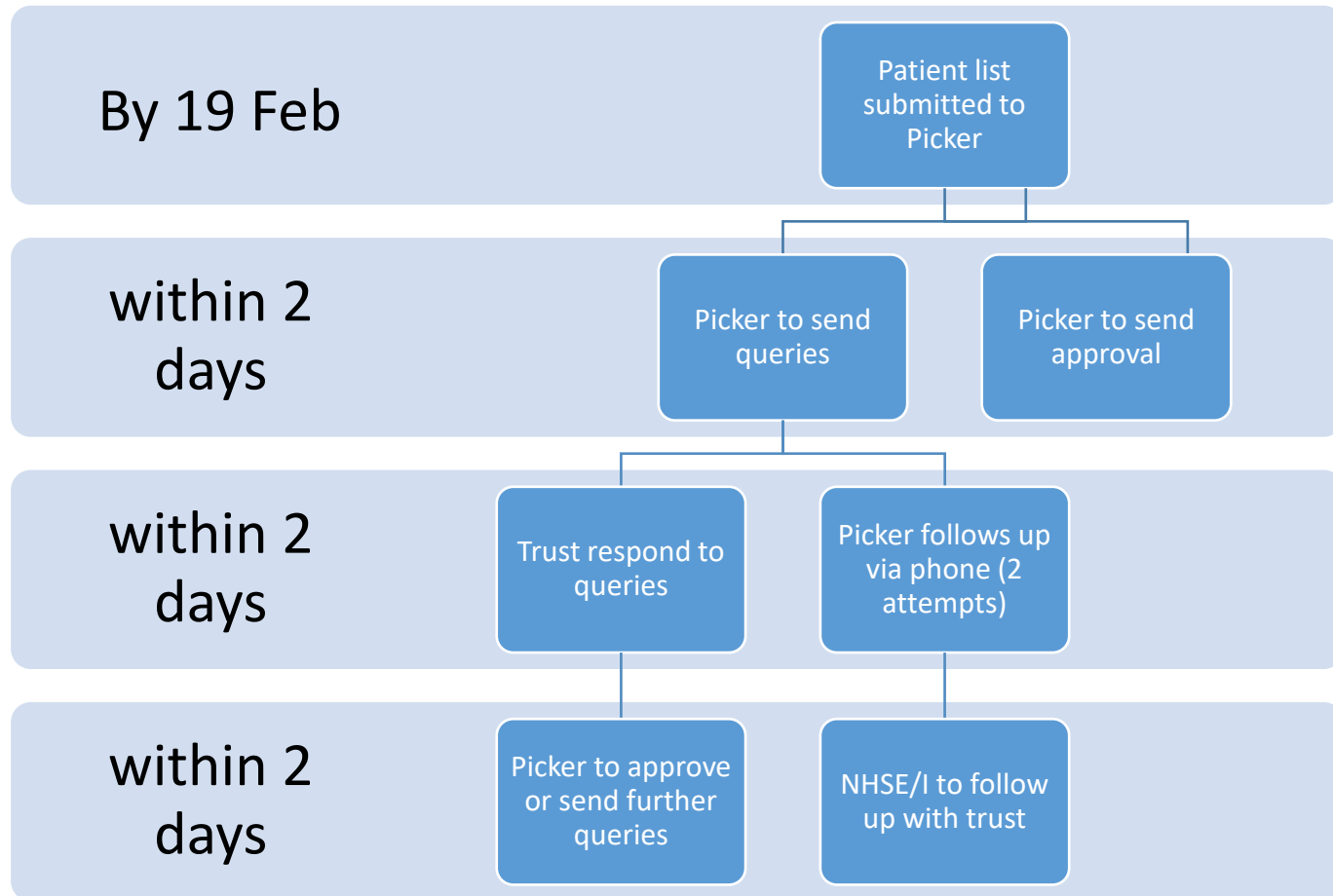
## Steps 7 & 8: After receiving permission, upload your patient list and email/phone file to Picker FTP

- Picker will provide instructions on how to upload the data via their secure file transfer site. **Please do not send the patient list using any other method. Patient lists should NEVER be sent by email.**

## Step 9: Be available for up to two weeks after submission for queries and clarification

- Once the sample checks have been completed, Picker will raise any queries directly with the trust. In some cases, where sampling errors are identified, trusts will be required to compile a new patient list, which would be subject to the same checking process described above.
- Once all queries and confirmation points have been resolved with the trust, the patient list can be approved for the next stage.

# Step 9: Be available for up to two weeks after submission for queries and clarification



# Key dates



# Timetable



Dates	Task
25-Jan	Data sharing agreements due from Trust survey leads (or other applicable staff). Note: must be received before patient list is submitted
25-Jan	Patient list submission start date – date for Trusts to aim toward. (Trusts can submit earlier than this if their list is ready).
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).
25 Jan- 5 Mar	Picker to check samples. Trusts to respond to queries
5-Mar	Final date patient samples can be approved for inclusion in the survey
19-Mar	Patient list finalised
w/c 29-Mar	Picker to conduct DBS trace and send the first survey invite
w/c 12-Apr	Picker to conduct DBS trace and send the first reminder
w/c 26-Apr	Picker to conduct DBS trace and send the final reminder
28-May	Fieldwork closes
2-Jun	Analysis and reporting begins

# Submission and follow-up

25th Jan

- **Trusts** to start submitting patient list to Picker

8th Feb

- **NHS England and NHS Improvement** to contact all trusts that have not responded to Picker

19th Feb

- **Last day** for **Trusts** to submit patient list to Picker
- **NHS England and NHS Improvement** to contact all trusts that have not submitted their patient list

5th Mar

- All samples must be approved by this date for **Picker** to send out mailing one
- **Trusts** that have not had their sample approved by this date **risk being excluded from the survey**

# Your role / Picker's role

# Your role



## **Survey leads:**

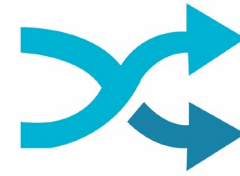
- Put together a team to carry out the 2020 U16 CPES
- Sign the data sharing agreement
- Ensure Picker have up-to-date contacts for your trust
- Complete the declaration form
- During fieldwork – inform Picker of any patients that contact the trust directly, wanting to opt-out of the survey

## **Data team members:**

- Compile your patient list using the template spreadsheet
- Submit your patient list as soon as possible (ideally by early February)
- Respond to Picker queries within 2 working days
- Ensure Picker are given any necessary contacts for planned leave

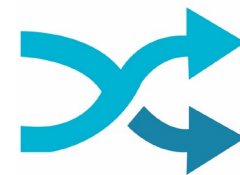
## **Clinical cancer team members:**

- Check the patient list before it is submitted to Picker to ensure that only patients are included who are aware of their diagnosis and have been treated by the cancer team



# Picker's role

- Send trusts the data sharing agreement
- Email trusts on 25<sup>th</sup> Jan asking for an expected submission date
- Support trusts in submitting as early as possible with any queries or issues they have over the sampling criteria
- Check the declaration form and let trusts know when to submit their patient list
- Provide trusts with the link and log-in information for submitting their patient list
- Check each patient list within 4 working days
- Follow up on unresolved queries within 2 working days



# Picker's role

- After sample approval, remove all duplicates and submit to DBS
- Post the questionnaires/invite letters and reminder mailings, and host online survey versions
- Provide and host a Freephone helpline number for patients to call
- Update trusts on progress throughout fieldwork
- Capture all data returned from patients
- Conduct analysis on final data and produce reports

# Next steps

Trusts to receive communication from Picker next Monday (25-Jan):

- Asking for an estimated sample submission date
- Containing reminders about sampling materials, deadlines
- Ask for the signed Data Sharing Agreement and signatories for the covering letter to be supplied to Picker

A copy of the webinar slides and recording will soon be made available.



Questions?



# Questions asked – and answers

**For the inclusion criteria of patients being aware of their diagnosis – Does this need to be confirmed by the service or a specific clinician?**

- It is up to the trust and may depend how the systems and processes they have in place. It is important that the Trust can verify that the parent or carer of the patient is aware of the cancer or tumour diagnosis to avoid causing distress to the survey recipients.

**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 2020, 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? It would be challenging to have all these instances.**

- 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 additional burden on trusts.

**We don't record parents phone data, is this a problem?**

- We are aware of potential variation in the availability of this data and how it is recorded/accessed. It's not a problem if your data is largely incomplete, as the collection of parent email and phone data is for exploratory purposes, to understand how complete the data is and whether it can be used for alternative methods in future survey waves.

# Questions asked – and answers

**Just noting that the checking process takes the longest part of creating the sample list.**

- Yes, we acknowledge that the checking process takes the longest and we are open to discuss timings to ease the burden on trusts. But this is an essential part of the sampling to avoid that patients do not receive a survey if they are unaware of their diagnosis.

**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 label 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 yet, 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.

# Questions asked – and answers

**ICD-10 code D76.1 isn't for a non-malignant brain, other CNS or intracranial tumour. It's for Haemophagocytic lymphohistiocytosis. Should it still be included?**

- Cancer-like conditions, such as Haemophagocytic lymphohistiocytosis and Langerhans cell histiocytosis, should be included in the sample as long as the patient was seen by a member of the cancer team for their treatment. Please exclude any instances in which a patient did not receive care for these conditions from a member of the cancer team.

Picker Institute Europe  
Buxton Court  
3 West Way  
Oxford OX2 0JB

Tel: + 44 (0) 1865 208100  
Fax: + 44 (0) 1865 208101

info@pickereurope.ac.uk  
www.picker.org

Charity registered in England and Wales: 1081688

Charity registered in Scotland: SC045048

Company limited by guarantee registered in England and Wales

# Thank you!

[under16cancersurvey@pickereurope.ac.uk](mailto:under16cancersurvey@pickereurope.ac.uk)

 **Picker**