2024 National Cancer Patient Experience Survey – sampling webinar for trusts

The presentation will start shortly!

Picker

www.picker.org

Agenda

- Background
- What is the same and what has changed for 2024?
- Sampling process and support materials
- Your patient list inc. potential sampling errors
- Submitting your patient list
- Important dates
- Your role / Picker’s role
- FAQ
- Questions

Background

Overview, impact and importance

The Cancer Patient Experience Survey has been designed to monitor national progress on cancer care; to provide information to drive local quality improvements; to assist commissioners and providers of cancer care; and to inform the work of the various charities and stakeholder groups supporting cancer patients.

- It is currently a mixed-mode survey (available to complete online and via paper)
- The first Cancer Patient Experience Survey was carried out in 2010
- The 2021 survey saw the introduction of a redeveloped questionnaire
- 2024 will allow for four years of trend data (comparisons between 2021, 2022, 2023 and 2024)

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/

Trust Section 251 requirements

- 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
- Trusts should submit their patient list using Picker’s secure site only
- To follow up on cases raised by Picker where a participant alerts us that they do not have cancer

Responding quickly to any cases raised is very important. Not only because of the potential distress caused to patients, but because of the potential impact on mailings and survey timings

Picker Section 251 requirements

- 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 subsequently remove these 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
- To follow up with the trust where a participant alerts us they are not eligible due to not having cancer
- Securely delete patient identifiable information 12 months after publication of all survey results

National data opt-out programme

The National Data Opt-out Programme is a service that allows patients to opt out of their confidential patient information being used for research and planning.

The National Cancer Patient Experience Survey is **exempt** from the National Data Opt-out.

All eligible patients are to be included in the patient list unless they have requested their details are not used following sight of survey pre-publicity (the survey’s dissent posters).

What is the same and what has changed for 2024?

Unchanged for 2024

Un-changed

- Sample period (April – June 2024)
- Eligibility criteria
- ICD-10 or ICD-11 codes accepted
- Use of our secure sample checking platform for uploading patient sample list
- Fieldwork methodology (3 mailings with option to complete online survey)
- Suite of outputs at trust, alliance and ICB level will be provided that allow for comparisons
- Continuing with the collection of email addresses and mobile phone numbers in the patient list (NOTE: we won't be contacting patients by text or email)
- Trend data (we will be able to compare 2021, 2022, 2023 and 2024 results)

Changed for 2024

Changed for 2024 - mobile data guidance

The process for submitting mobile phone data is the same as last year. However, we have added text in the sampling guidance to highlight the importance of submitting mobile data (where available) and provide further information on submission:

- This data will not be used to contact patients this year. We would like to explore whether mobile data can be used to send text message reminders in future years of NCPES, with the aim to improve response rate and/or online completion.
- Eligible patients without mobile numbers should not be removed from the sample. **The more data submitted as part of the sample the better we can understand potential methodology changes for the future.**
- We will not be querying the quality of these with you to avoid delaying the sampling process. If collating this data is causing delays in submitting your sample, please contact the team for advice on how to proceed.

Changed for 2024 - questionnaire

The questionnaire for 2024 can be found on the website - https://www.ncpes.co.uk/survey-instructions/

There have been a few small changes for this year…

Question 69

2023

Can we contact you in the future to tell you about other surveys or research about your healthcare experiences? These may be run by non-NHS organisations, such as cancer charities. However, your contact details will never be shared with these organisations.

2024

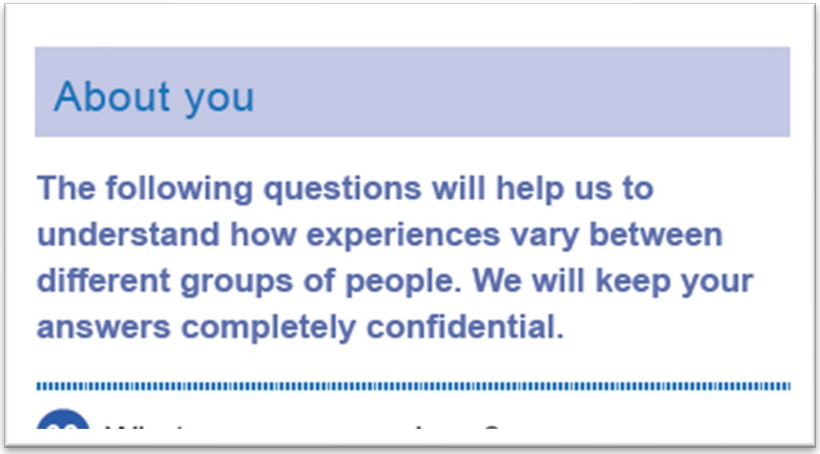
Can NHS England contact you in the future to tell you about other surveys or research about your healthcare experiences?

Changed for 2024 - questionnaire

About you section (questions 63 to question 71)

Additional introductory text for 2024

The following questions will help us to understand how experiences vary between different groups of people. We will keep your answers completely confidential.



About you

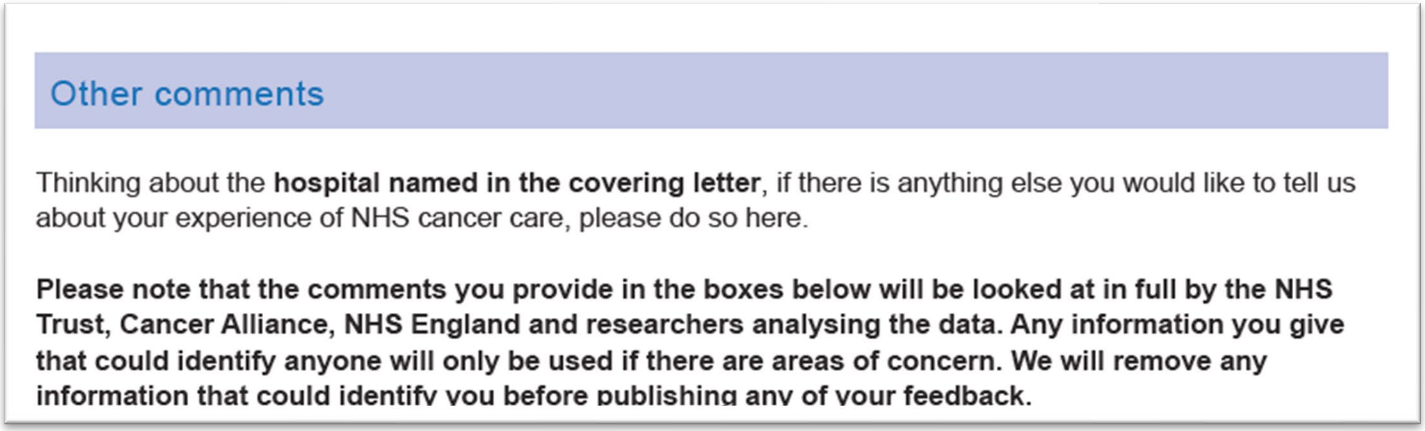
The following questions will help us to understand how experiences vary between different groups of people. We will keep your answers completely confidential.

Changed for 2024 - questionnaire

Freetext questions:

2024

Please note that the comments you provide in the boxes below will be looked at in full by the NHS Trust, Cancer Alliance, NHS England and researchers analysing the data. Any information you give that could identify anyone will only be used if there are areas of concern. We will remove any information that could identify you before publishing any of your feedback.



Other comments

Thinking about the **hospital named in the covering letter**, if there is anything else you would like to tell us about your experience of NHS cancer care, please do so here.

Please note that the comments you provide in the boxes below will be looked at in full by the NHS Trust, Cancer Alliance, NHS England and researchers analysing the data. Any information you give that could identify anyone will only be used if there are areas of concern. We will remove any information that could identify you before publishing any of your feedback.

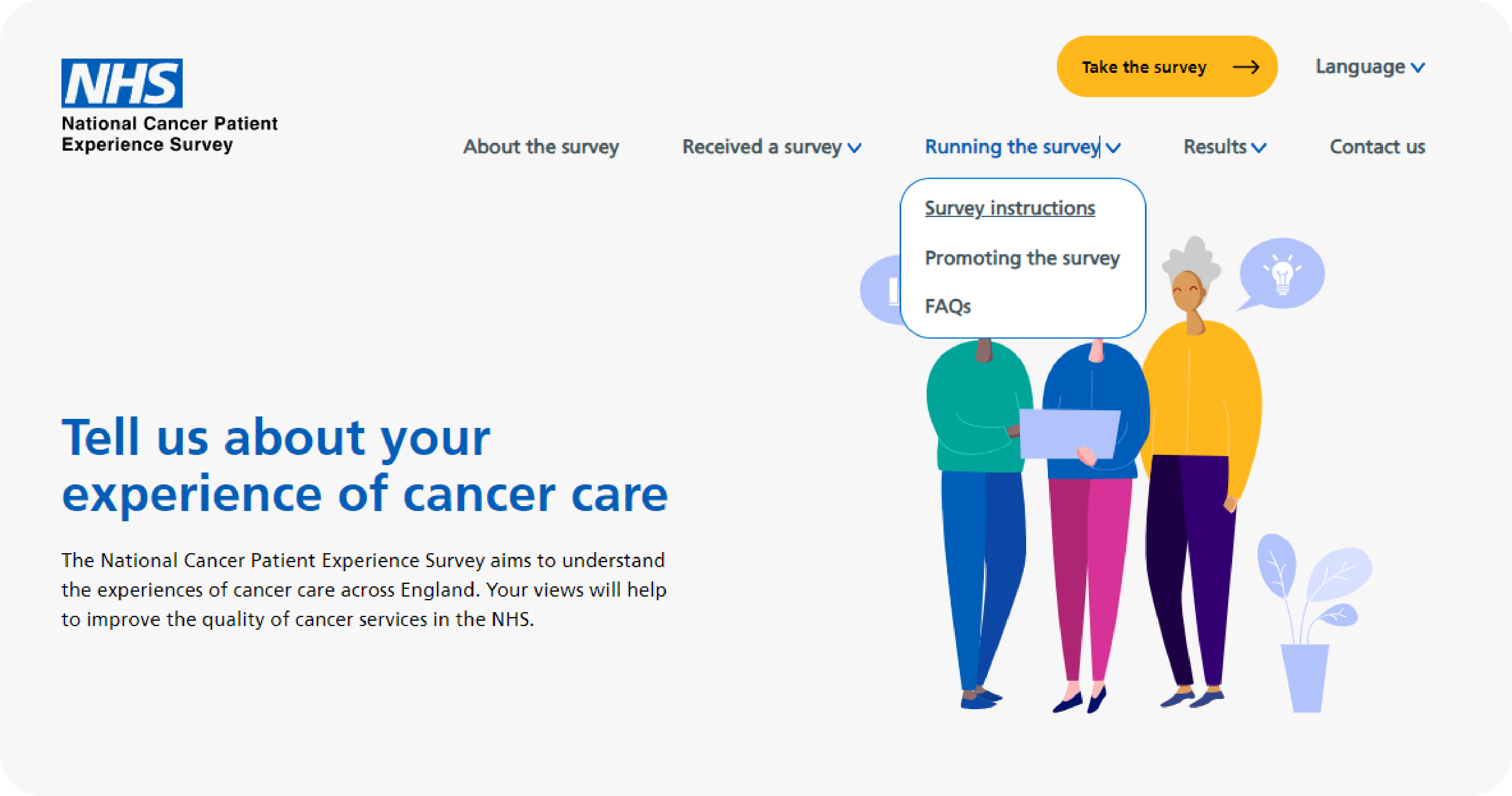
Sampling process and support materials

Sampling process

- Display dissent posters. Keep a record of any patients who dissent to participate.
- Compile a list of eligible patients
- Perform checks on the sample
- Remove deceased patients from your sample by submitting to the Demographic Batch Service (DBS) or equivalent
- Complete the patient list declaration form and send it to Picker via cpes@pickereurope.ac.uk
- When you receive confirmation that the declaration form is approved, submit your sample via the sample checking platform
- Be available for up to two weeks after data submission to respond to any queries on your sample

Guidance materials

https://www.ncpes.co.uk/survey-instructions/



Tell us about your experience of cancer care

The National Cancer Patient Experience Survey aims to understand the experiences of cancer care across England. Your views will help to improve the quality of cancer services in the NHS.

Guidance materials

Dissent posters and leaflets

NHS

Help us improve cancer care for everyone

If you have had treatment here you may soon be asked to take part in NHS England's **National Cancer Patient Experience Survey**. The survey helps us monitor what's working well and what could be improved for future cancer patients.

All NHS patients who have cancer related care or treatment as an inpatient or day case in April, May or June 2024 will be contacted to take part in the survey.

Taking part is voluntary.

The survey will be carried out by an independent organisation working under contract to NHS England. They will use your personal details to contact you. They will only use your details to carry out the survey. These details will be provided by this NHS trust. Your personal information will be handled securely and confidentially. We will not publish any information which might identify you.

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

Dissent posters (available in 11 languages) were sent out in March 2024.

It is a section 251 requirement to display these materials during the sampling frame of April, May and June.

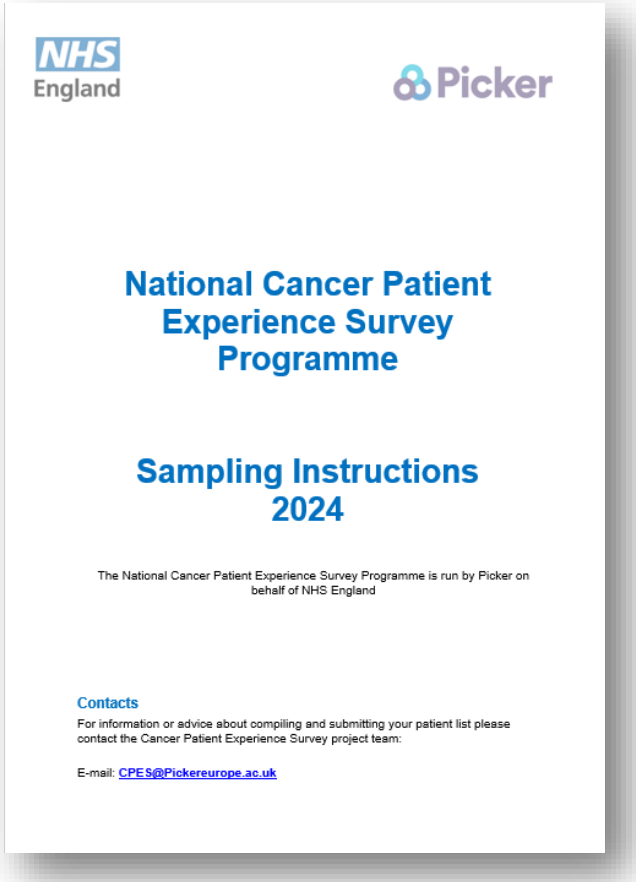
Patients will also have the opportunity to opt out through calling our helpline or sending back a blank questionnaire.

The dissent posters are available on the survey website to download and display so that patients are aware.

Opt out patients should be recorded and removed from your patient list **before submitting to Picker**.

Guidance materials

Sampling Guidance



NHS England

Picker

National Cancer Patient Experience Survey Programme

Sampling Instructions 2024

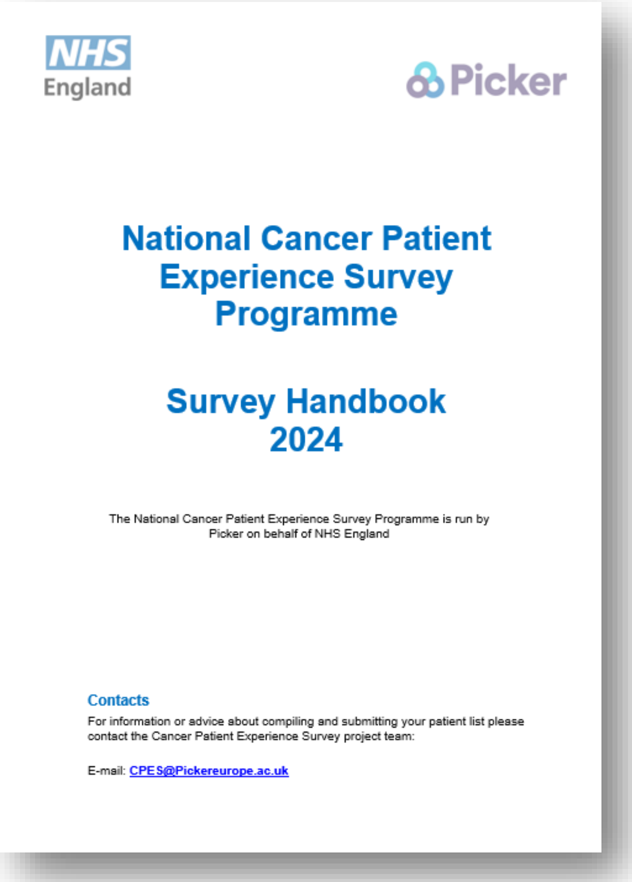
The National Cancer Patient Experience Survey Programme is run by Picker on behalf of NHS England

Contacts

For information or advice about compiling and submitting your patient list please contact the Cancer Patient Experience Survey project team:

E-mail: CPES@Pickereurope.ac.uk

Survey instructions



NHS England

Picker

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Survey Handbook 2024

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Contacts

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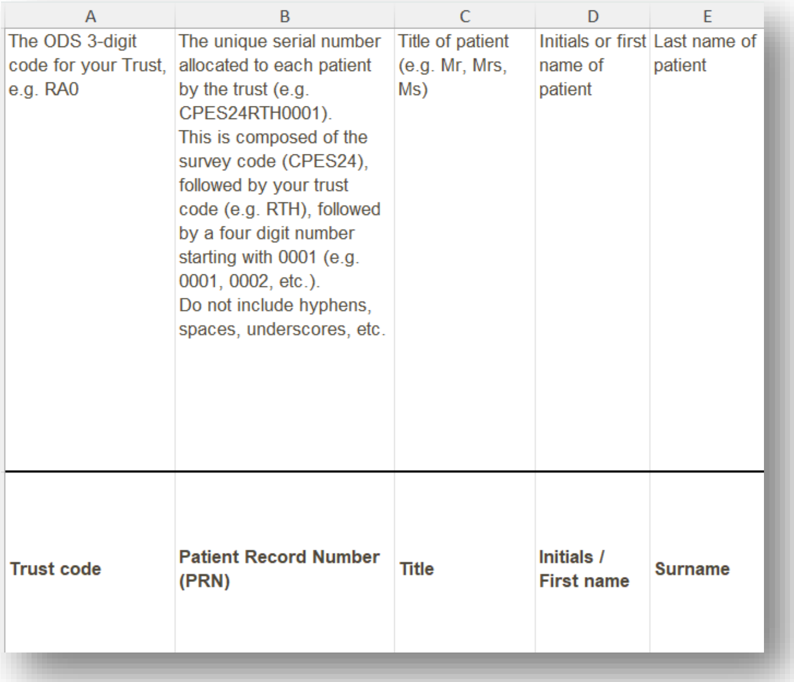
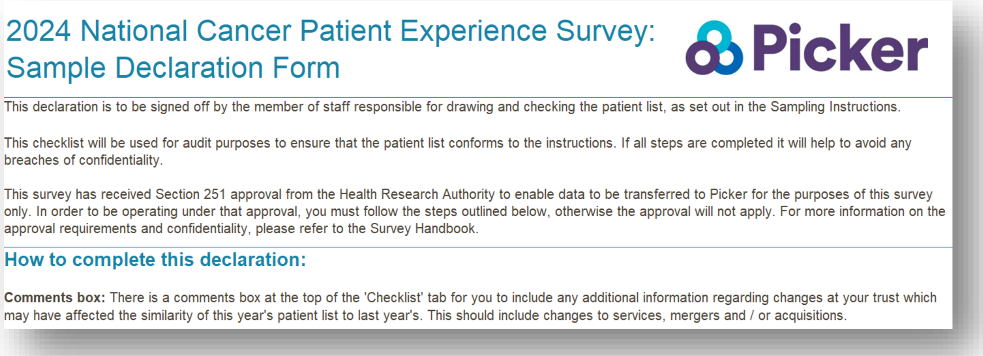
Guidance materials

Excel template



A	B	C	D	E
The ODS 3-digit code for your Trust, e.g. RA0	The unique serial number allocated to each patient by the trust (e.g. CPES24RTH0001). This is composed of the survey code (CPES24), followed by your trust code (e.g. RTH), followed by a four digit number starting with 0001 (e.g. 0001, 0002, etc.). Do not include hyphens, spaces, underscores, etc.	Title of patient (e.g. Mr, Mrs, Ms)	Initials or first name of patient	Last name of patient
Trust code	**Patient Record Number (PRN)**	**Title**	**Initials / First name**	**Surname**

Declaration form



2024 National Cancer Patient Experience Survey: Sample Declaration Form

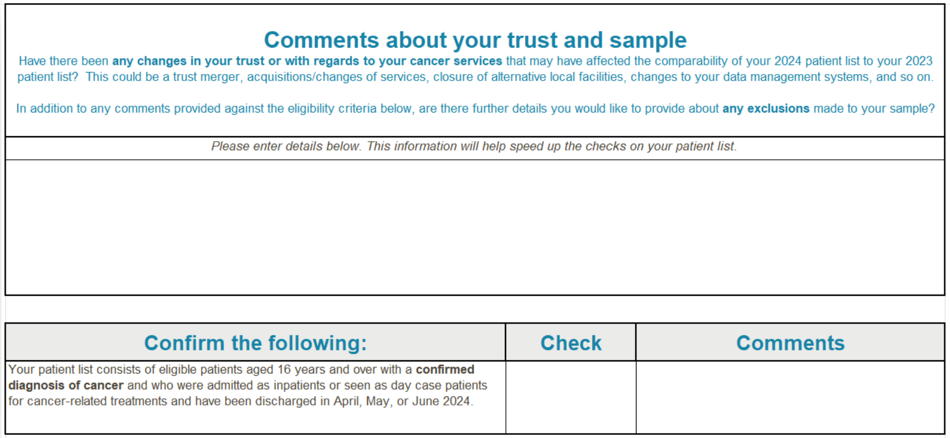
This declaration is to be signed off by the member of staff responsible for drawing and checking the patient list, as set out in the Sampling Instructions.

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:

Comments box: There is a comments box at the top of the 'Checklist' tab for you to include any additional information regarding changes at your trust which may have affected the similarity of this year's patient list to last year's. This should include changes to services, mergers and / or acquisitions.



Comments about your trust and sample

Have there been **any changes in your trust or with regards to your cancer services** that may have affected the comparability of your 2024 patient list to your 2023 patient list? This could be a trust merger, acquisitions/changes of services, closure of alternative local facilities, changes to your data management systems, and so on.

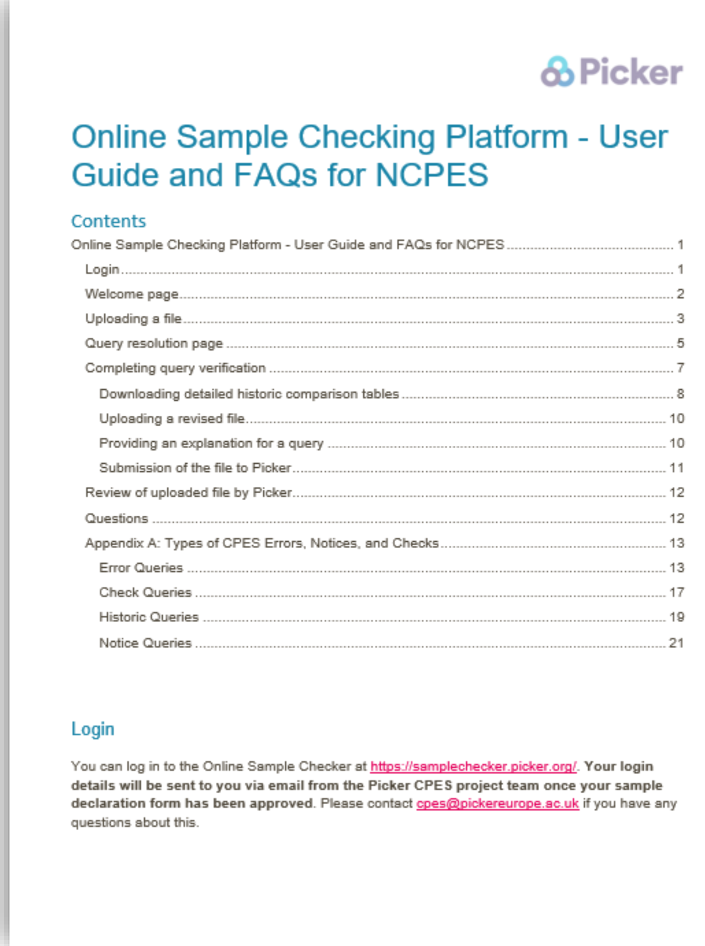
In addition to any comments provided against the eligibility criteria below, are there further details you would like to provide about **any exclusions** made to your sample?

Please enter details below. This information will help speed up the checks on your patient list.

Confirm the following:	Check	Comments
Your patient list consists of eligible patients aged 16 years and over with a **confirmed diagnosis of cancer** and who were admitted as inpatients or seen as day case patients for cancer-related treatments and have been discharged in April, May, or June 2024.		

Guidance materials

Sample checker user guide



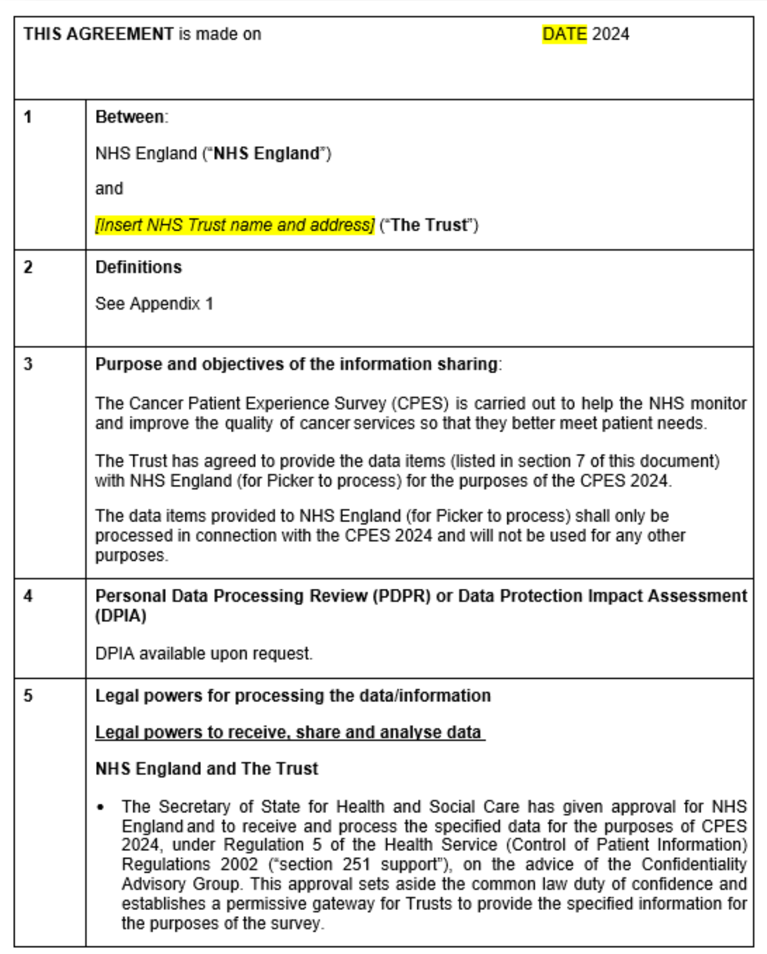
Online Sample Checking Platform - User Guide and FAQs for NCPES

Contents

Login

You can log in to the Online Sample Checker at https://samplechecker.picker.org/. **Your login details will be sent to you via email from the Picker CPES project team once your sample declaration form has been approved**. Please contact cpes@pickereurope.ac.uk if you have any questions about this.

Data sharing agreement



THIS AGREEMENT is made on	DATE 2024
1	**Between**: NHS England ("**NHS England**") and *[Insert NHS Trust name and address]* ("**The Trust**")
2	**Definitions** See Appendix 1
3	**Purpose and objectives of the information sharing**: The Cancer Patient Experience Survey (CPES) is carried out to help the NHS monitor and improve the quality of cancer services so that they better meet patient needs. The Trust has agreed to provide the data items (listed in section 7 of this document) with NHS England (for Picker to process) for the purposes of the CPES 2024. The data items provided to NHS England (for Picker to process) shall only be processed in connection with the CPES 2024 and will not be used for any other purposes.
4	**Personal Data Processing Review (PDPR) or Data Protection Impact Assessment (DPIA)** DPIA available upon request.
5	**Legal powers for processing the data/information** **Legal powers to receive, share and analyse data** **NHS England and The Trust** • The Secretary of State for Health and Social Care has given approval for NHS England and to receive and process the specified data for the purposes of CPES 2024, under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 ("section 251 support"), on the advice of the Confidentiality Advisory Group. This approval sets aside the common law duty of confidence and establishes a permissive gateway for Trusts to provide the specified information for the purposes of the survey.

Your patient list

Eligibility criteria – Who to include ✓

- Patients discharged between 1st April to 30th June 2024
- Patients…
    - with a **confirmed primary diagnosis of cancer**
        - ICD-10 codes of C00-C43, C45-C83, C85-C97 and D05 or corresponding ICD-11 codes
    - who have been admitted as an inpatient or a day case patient for **cancer-related treatment**
    - who were discharged **during** the sampling frame
    - age 16 and older **at the time they were discharged**

- Please **include** duplicate records. The list must include all eligible instances of care, so some patients may appear more than once

Potential sampling errors

Remember:

- Only include patients discharged during the sampling frame (1st April to 30th June 2024)
- Ensure that emergency admissions are included
- Include all eligible patients, not just those who are newly diagnosed

Please make sure that you **include**:

- patients with an ICD-10 code of D05

Eligibility criteria – Who to exclude

People…

- who are deceased
- Without a confirmed diagnosis of cancer including patients who have been given a holding diagnosis code with pending results
- With a patient classification of 5
- With an ICD-10 code of C44 (C44.0-C44.9) or ICD-11 code 2C3Z
- With an ICD-10 code of C84 (C84.0-C84.9) or ICD-11 codes 2B01, 2B02, 2A90.C, 2B2Z, 2A90.A, 2A90.B, 2B0Z and 2B2Z
- Not seen by the NHS
- That are current inpatients
- That are solely treated as outpatients
- That do not have a UK postal address
- That do not have enough address information for delivery
- That have opted out from taking part in the survey (for example as a result of seeing a dissent poster)

Potential sampling errors

Please **exclude**:

- outpatients
- patients with an ICD-10 code of C44 or C84 (or equivalent ICD-11 code)
- cancer patients that had been seen at the trust but not for cancer-related treatment

Cancer related treatment

Examples include the below if delivered as an inpatient or a day case:

- Treatments directly related to cancer such as all forms of chemotherapy, cryotherapy, hormone therapy, immunotherapy, laser treatment, light therapy, palliative surgery (debulking etc.), radiotherapy, radioisotope therapy, surgical resections.
- Treatments for symptoms related to cancer such as cancer related anaemia, malignant pleural effusions and ascites, infections related to the cancer site, poor nutrition caused by the cancer, urinary problems caused by cancer.

A patient should not be included if they no longer have cancer and are receiving treatment for something that occurred during their cancer treatment years ago. An example of this would be if they had breast cancer 5 years ago, they're in remission but they'd been admitted in the sampling period for reconstruction surgery. This patient would be excluded.

If you have any specific scenarios that you're unsure of, please send them across in an email or give us a call and we're happy to help with making a decision.

Outpatients

- It is recognised that CPES currently excludes patients who have solely had outpatient appointments during the sampling period.
- Over the last few years NHSE, with support from the CPES Advisory Group, have explored options for the inclusion of outpatients (inc. asking trusts to include outpatients in their sample and the use of cancer waiting times data amongst others).
- As yet, we have not found an option that meets four key criteria - timely, accurate, consistent, and as low burden as possible.
- Therefore, the sampling approach for CPES24 is unchanged.

Implications of sampling errors

- The online sample checker and Picker staff check that patient lists have been drawn correctly according to the sampling criteria. This is to aid you in avoiding common errors prior to fieldwork commencing.
- They are also flagged to you in order to help you avoid errors in future iterations of the survey.
- It is important that errors are identified as they can lead to delays in the survey process and/or poor data quality.
- Depending on the nature of the error, it may not be possible to provide historical data comparisons during the reporting stage of the survey.

Important note regarding cases of ‘no cancer’

It is the responsibility of trusts to ensure the patient list **only** includes eligible patients who have a **confirmed** diagnosis of cancer whose admission during the sampling period was **in relation** to their cancer diagnosis.

Any reported cases of ‘no cancer’ by patients during fieldwork will be looked into by Picker and the Trust. Where there is more than one identified case for a Trust, we will pause the survey mailings for that Trust whilst eligibility is investigated. It is therefore important that cases are investigated quickly by Trusts so that patients can be re-assured, and fieldwork can proceed on schedule.

Submitting your patient list

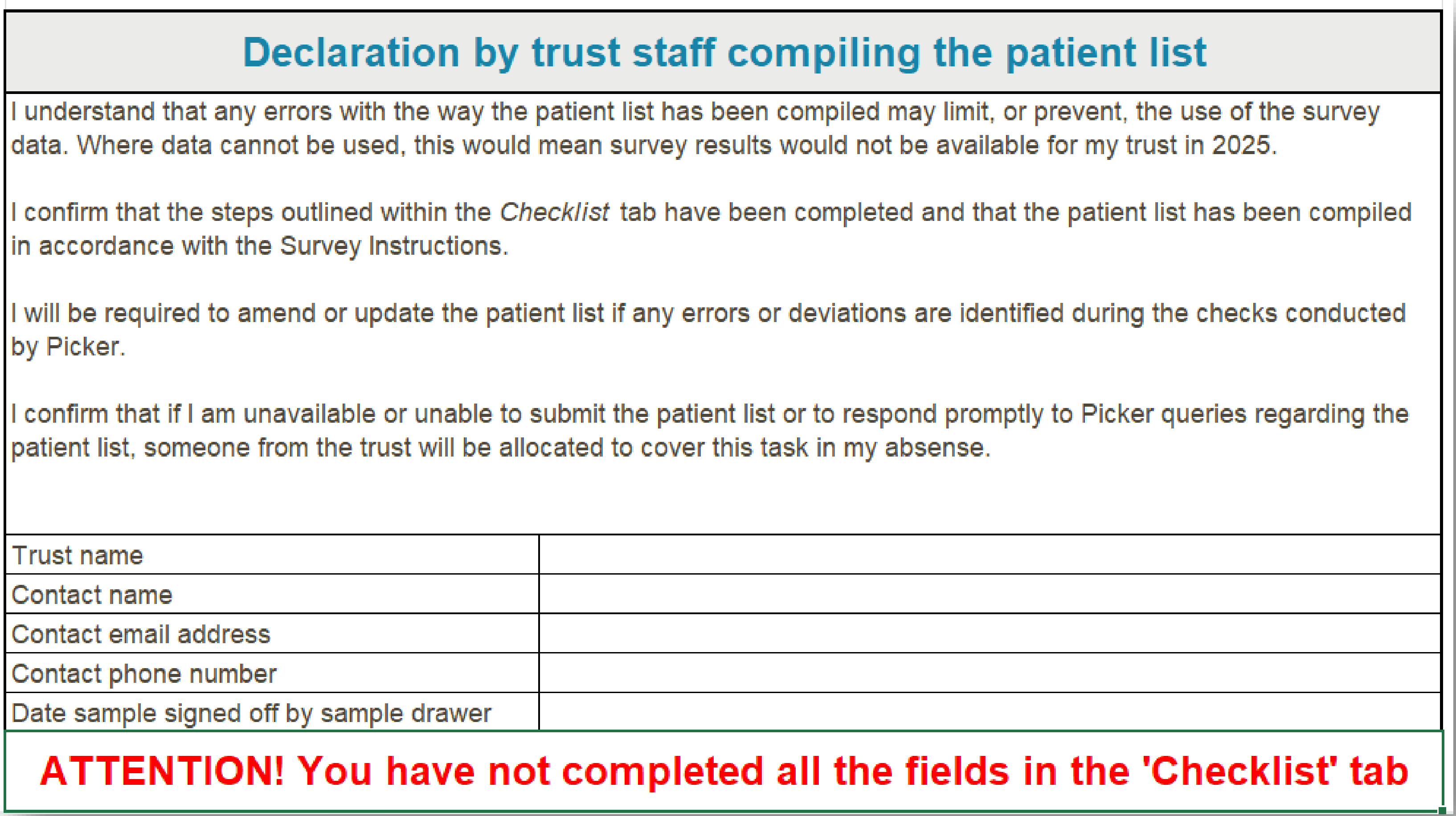
Submitting your patient list

- Make sure you have the relevant permissions to share the data by completing and submitting the Data Sharing Agreement

- 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 the form to cpes@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/

Patient list declaration form



Declaration by trust staff compiling the patient list

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 2025.

I confirm that the steps outlined within the *Checklist* tab have been completed and that the patient list has been compiled in accordance with the Survey Instructions.

I will be required to amend or update the patient list if any errors or deviations are identified during the checks conducted by Picker.

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 absense.

Trust name	
Contact name	
Contact email address	
Contact phone number	
Date sample signed off by sample drawer	

ATTENTION! You have not completed all the fields in the 'Checklist' tab

Patient list declaration form

Purpose – to ensure all necessary checks have been completed as per the guidance and so Picker know who to contact for any queries.

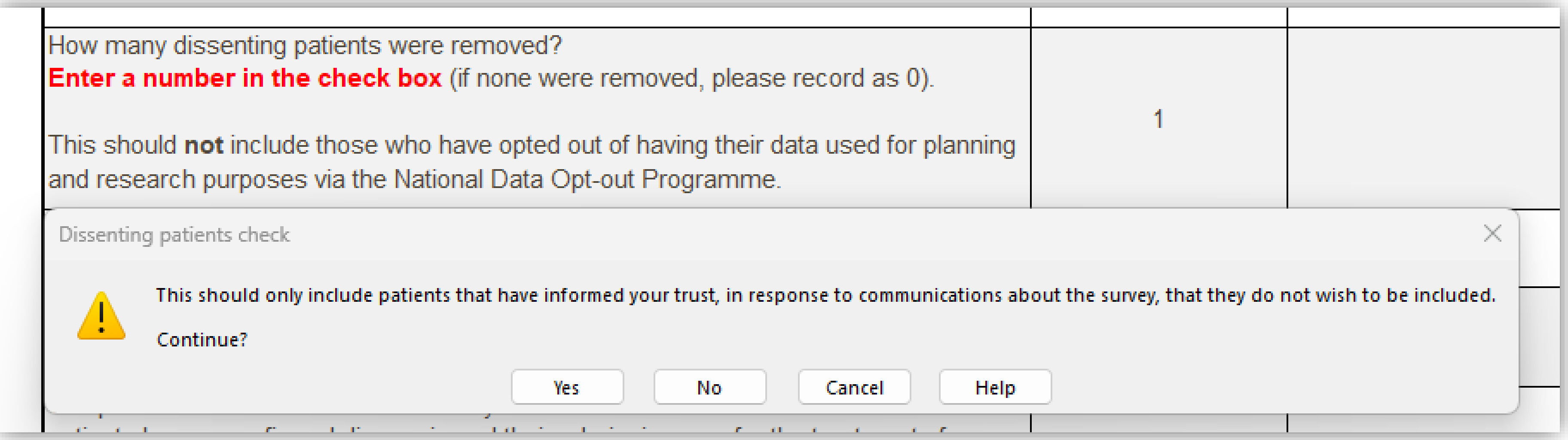
The member of staff responsible for compiling and checking the patient list must complete the Patient List Declaration Form and send to Picker before submitting their patient list.

To complete the declaration form:

- Provide information on any changes that have occurred at your trust **in the last year.**
- Complete each check in the checklist
- Provide an explanation for any ‘NA’ entered for a check
- Sign and date the declaration form

Patient list declaration form

Dissenting patients check



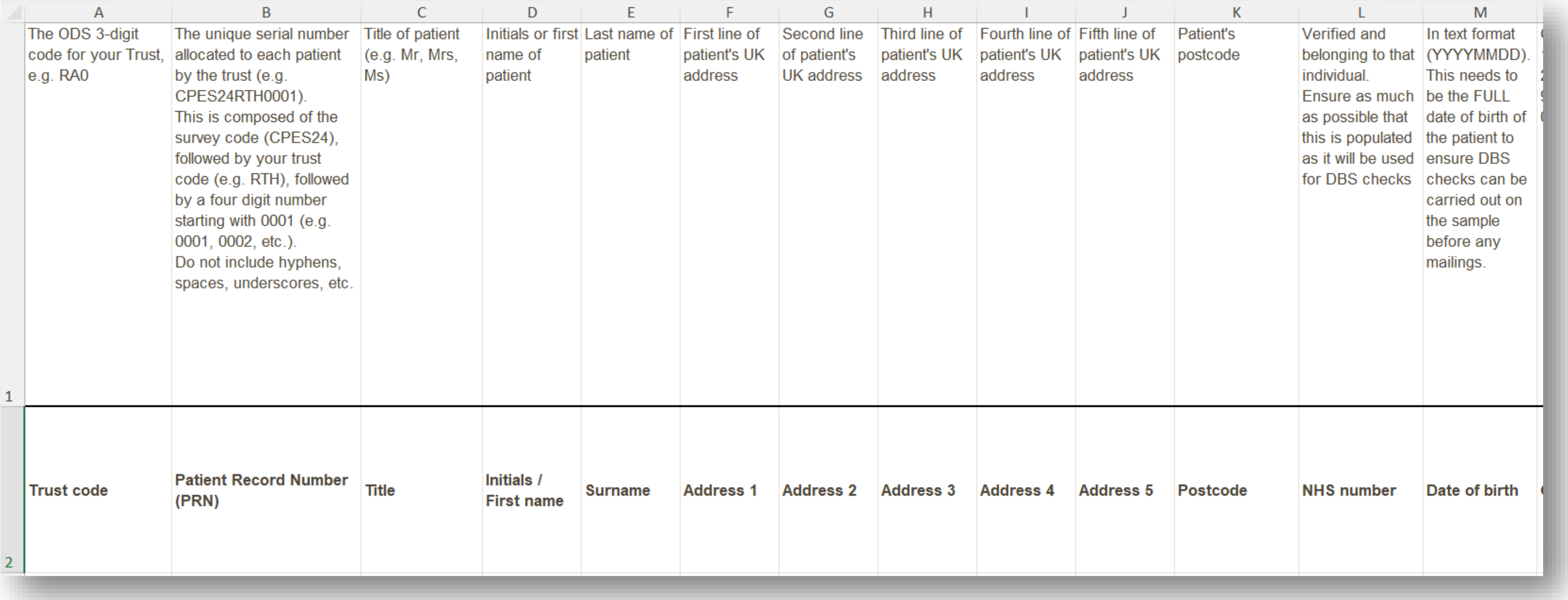
How many dissenting patients were removed? **Enter a number in the check box** (if none were removed, please record as 0). This should **not** include those who have opted out of having their data used for planning and research purposes via the National Data Opt-out Programme.	1

Dissenting patients check

This should only include patients that have informed your trust, in response to communications about the survey, that they do not wish to be included.

Continue?

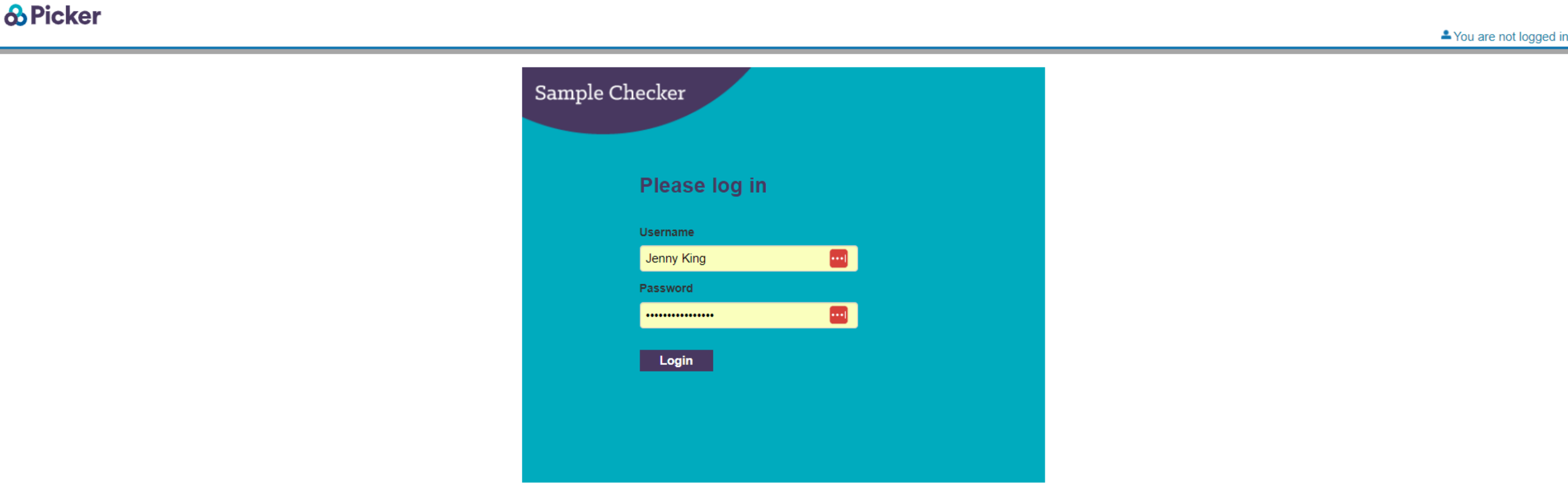
Patient list template spreadsheet



	A	B	C	D	E	F	G	H	I	J	K	L	M
1	The ODS 3-digit code for your Trust, e.g. RA0	The unique serial number allocated to each patient by the trust (e.g. CPES24RTH0001). This is composed of the survey code (CPES24), followed by your trust code (e.g. RTH), followed by a four digit number starting with 0001 (e.g. 0001, 0002, etc.). Do not include hyphens, spaces, underscores, etc.	Title of patient (e.g. Mr, Mrs, Ms)	Initials or first name of patient	Last name of patient	First line of patient's UK address	Second line of patient's UK address	Third line of patient's UK address	Fourth line of patient's UK address	Fifth line of patient's UK address	Patient's postcode	Verified and belonging to that individual. Ensure as much as possible that this is populated as it will be used for DBS checks	In text format (YYYYMMDD). This needs to be the FULL date of birth of the patient to ensure DBS checks can be carried out on the sample before any mailings.
2	**Trust code**	**Patient Record Number (PRN)**	**Title**	**Initials / First name**	**Surname**	**Address 1**	**Address 2**	**Address 3**	**Address 4**	**Address 5**	**Postcode**	**NHS number**	**Date of birth**

Submitting your patient list

https://samplechecker.picker.org/



Please log in

Username: Jenny King

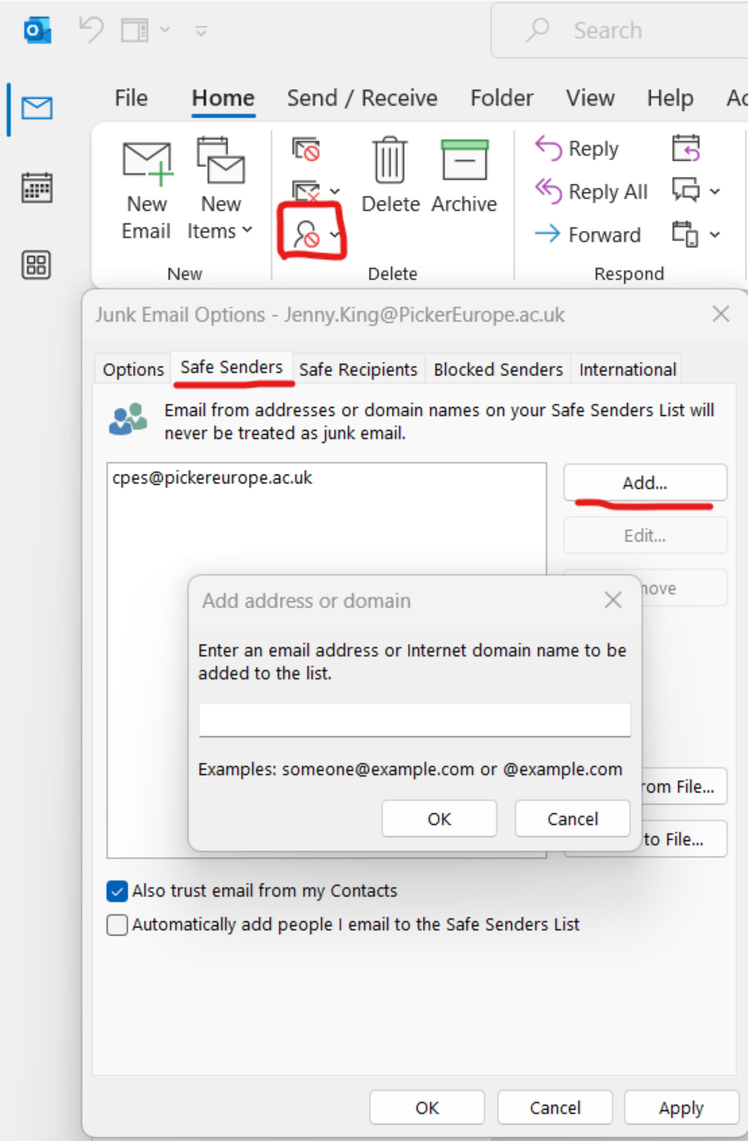
Password: ••••••••••••••••

Submitting your patient list

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

Safe Sender List



Junk Email Options - Jenny.King@PickerEurope.ac.uk

Email from addresses or domain names on your Safe Senders List will never be treated as junk email.

cpes@pickereurope.ac.uk

Add address or domain

Enter an email address or Internet domain name to be added to the list.

Examples: someone@example.com or @example.com

☑ Also trust email from my Contacts

☐ Automatically add people I email to the Safe Senders List

- Remember to add the Picker email address to your safe sender list!
- This is so that Picker emails don't go to junk, and you don't miss important communications regarding your sample and survey fieldwork

cpes@pickereurope.ac.uk

Important dates

Dates for submission and follow-up†

15-Aug	• Deadline for trusts to submit data sharing agreements (DSAs)
15-Aug	• Trusts to start submitting patient sample declaration forms and lists to Picker
6-Sep	• Deadline for trusts to confirm cover letter signatory information and trust logos
9-Sep	• NHS England to contact all trusts that have not responded to Picker
16-Sep	• Last day for trusts to submit their patient list to Picker • NHS England to contact all trusts who have not submitted their patient list
20-Sep	• All samples must be approved by this date for Picker to send out mailing one

†Note: Although final submission deadline is 16 Sept, we encourage submission early Sept as sample approval can take a few weeks

Your role / Picker's role

Your role

Survey leads:

- Ensure Data Sharing Agreement is signed
- Ensure Picker have up-to-date contacts for your trust
- Complete the declaration form
- Confirm cover letter information
- During fieldwork – inform Picker of any patients that contact the trust directly, wanting to opt-out of the survey
- During fieldwork – support Picker to investigate cases of ‘no cancer’ (NOTE: it is important this is done quickly)

Data team members:

- Compile your patient list using the template spreadsheet
- Submit your patient list as soon as possible
- 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
- During fieldwork – support Picker to investigate cases of ‘no cancer’

Picker's role

- Send trusts the data sharing agreement
- 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 and email address for patients
- Investigate with trusts cases of ‘no cancer’
- Capture all data returned from patients
- Conduct analysis on final data and produce reports

FAQ

FAQ

Question	Answer
If patients opt-out nationally (to all patient experience surveys), does this apply to this survey?	No. The NCPES is **exempt** from the National Data Opt-Out Programme. This should not be applied to the NCPES patient list. However, if someone has indicated through seeing survey communications that they do not want to take part, then please exclude them from the sample.
If a patient contacts Picker to opt-out, would Picker make them aware that this only opts them out of the NCPES 2024 survey and that they would need to contact the trust to be opted out of other surveys?	Yes, Picker has guidance for call and email handlers to instruct patients that they would only be opted out of this year's NCPES survey and would need to contact the trust in order to be opted out of wider surveys.
Who should sign the Data Sharing Agreement (DSA)?	The DSA should be signed by whoever you consider most appropriate for it in the trust. This could be the survey lead, Caldicott Guardian or Chief Executive, for instance.

FAQ

Question	Answer
Will you need Caldicott Guardian clearance for the declaration form from our trust or will the Data Sharing Agreement cover this?	No, the Caldicott Guardian is not required to sign off on the declaration form. The transfer of data from your trust to Picker will be covered from the Data Sharing Agreement.
Will Picker be requesting local deceased checks before each mailing?	No. You are required to do a local check for deceased patients only before submitting your initial patient list to Picker. Picker will be doing DBS checks before each mailing. However if a trust wishes to do a local check before the second and third mailing, then this is definitely welcomed. The mailing dates will be sent out once they are confirmed, alongside deadlines for local deceased checks.
Should we exclude dementia patients?	No. Dementia patients should be included as long as they meet all other eligibility criteria. It is important to provide these patients with the opportunity to give feedback.

FAQ

Question	Answer
What do we mean by cancer related treatment?	Examples include the below if delivered as an inpatient or a day case: Treatments directly related to cancer such as all forms of chemotherapy, cryotherapy, hormone therapy, immunotherapy, laser treatment, light therapy, palliative surgery (debulking etc.), radiotherapy, radioisotope therapy, surgical resections. Treatments for symptoms related to cancer such as cancer related anaemia, malignant pleural effusions and ascites, infections related to the cancer site, poor nutrition caused by the cancer, urinary problems caused by cancer. A patient should not be included if they no longer have cancer and are receiving treatment for something that occurred during their cancer treatment years ago. An example of this would be if they had breast cancer 5 years ago, they're in remission but they'd been admitted in the sampling period for reconstruction surgery. This patient would be excluded. If you have any specific scenarios that you're unsure of, please send us an email or give us a call and we're happy to help with making a decision.

FAQ

Question	Answer
Why are patients with C44 and C84 ICD-10 codes excluded?	To support with the running of the survey this year, we've kept the sampling criteria the same as in previous years, which means excluding C44 and C84 codes. Historically, where we have had cases of patients with these ICD-10 codes being wrongly included in the survey we have found that they have not always been clear that they have cancer resulting in a high volume of freephone calls/queries being received.
Why are outpatients excluded?	There currently is no way of standardising the capture of knowledge regarding outpatients across the Trusts. Any way to add outpatients to the sample list does not meet the criteria agreed with Cancer Patient Experience Advisory Group. This being a solution that is timely, accurate, consistent and low burden.

FAQ

Question	Answer
Should patients who were only seen for diagnostic tests be included in the sample?	No. Please exclude patients who were seen only for diagnostic tests, as there is a greater risk around these patients having not received their diagnosis yet. In addition, if the patient did receive a diagnosis, there is a greater likelihood that they will be sampled from another point in their care pathway (e.g. if they were seen for treatment later/at another Trust).
Should people receiving systematic anti-cancer therapy (SACT) as an outpatient be included?	No. People receiving SACT as an outpatient should not be included. Outpatients are currently excluded from the survey as there is no way of standardising the capture of knowledge regarding outpatients across the Trusts. People receiving SACT as a day case or inpatient should be included.
Can we include patients who live in Northern Ireland, Scotland, and Wales?	Yes. As long as patient’s meet all other eligibility criteria then they should be included. However, if they are without a UK address then they should be excluded.

FAQ

Question	Answer
When patients appear on more than one trust list will they get multiple questionnaires? **How will you choose which trust is on the questionnaire to the patient?**	No. Each patient will only get one questionnaire. Once we have a full list of patients, we will then remove duplicates, keeping the record with the most recent treatment discharge date. Patients will therefore be asked to think about the hospital at which they had their most recent discharge during this period.
Should we include patients without an NHS number?	Yes. As long as the patients meet all other eligibility criteria they should be included.
We don't have email addresses and phone numbers for everyone, is that OK?	Yes. Please provide the data that you do have as it will help us understand the % of records in the NCPES sample that do have this information.
We collect phone numbers but don't know if it is a mobile number or a home telephone number, should we still include this information?	Yes. If it is possible to check that numbers are mobile not landline then please do so. This should be either an 11-digit number starting with '07' or a 12-digit number starting with '+44 7'. However, please don't let this delay submission of your patient list. If you are unable to carry out this check, please send us all numbers.

FAQ

Question	Answer
Are there provisions for people whose first language isn’t English?	Yes. Patients have the option to complete the questionnaire using a translation service offered by our freephone provider. The survey website has a translated section in 14 languages communicating key survey information to patients to support survey completion.
Are patients sent any subsequent surveys as a result of their answers to this survey?	Yes, they can be. If a patient ticks yes to Q69 in the questionnaire (agreeing to NHS England contacting you in future to tell you about other surveys or research about your healthcare experiences) then they could be contacted with a follow up questionnaire from research organisations that have requested and been approved by NHS England to use the data for a cancer-related questionnaire. If a patient ticks no to this question, then their data would not be used for any further contact from us, NHS England nor any other research organisation.
When will the 2024 NCPES results be published?	Publication is expected in summer 2025.

Any further questions?

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