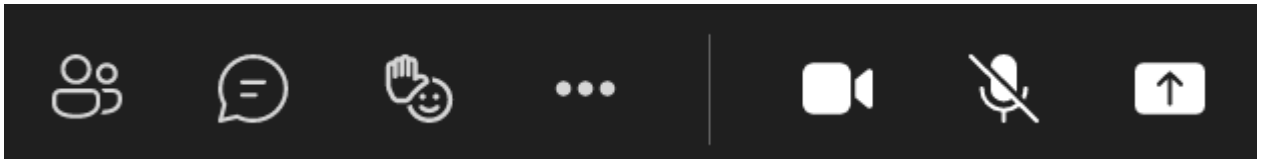
2026 National Cancer Patient Experience Survey – sampling webinar for trusts

The presentation will start shortly!

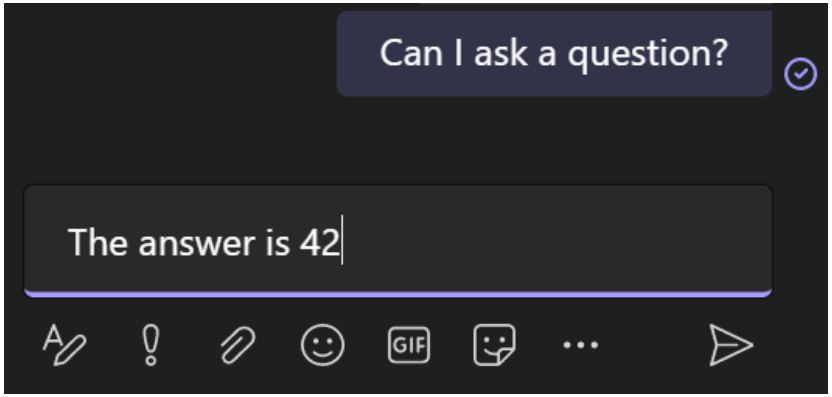
Housekeeping

- Keep yourself muted whilst the presentations are ongoing



Housekeeping

- Keep yourself muted whilst the presentations are ongoing
- Add your thoughts/questions to the chat



Housekeeping

- Keep yourself muted whilst the presentations are ongoing
- Add your thoughts/questions to the chat
- Pop your hand up if you have a question – we have a lot of slides to get through so will tackle questions over the mic at the end

Housekeeping

- Keep yourself muted whilst the presentations are ongoing
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- Pop your hand up if you have a question
- All slides will be circulated after the event

Housekeeping

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

Agenda

- Background
- What is the same and what has changed for 2026?
- Sampling process and support materials
- Comfort break
- Your patient list, including potential sampling errors
- Submitting your patient list
- Important dates
- Your role / Picker’s role
- FAQs
- Questions

Background

Overview, impact and importance

The National Cancer Patient Experience Survey (NCPES) 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 National Cancer Patient Experience Survey was carried out in 2010, and the 2021 survey saw the introduction of a redeveloped questionnaire
- 2026 will allow for six years of trend data for the majority of questions

Section 251

Section 251 requirements

The survey has received Section 251 support 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: Programmes to which the National Data Opt-Out should not be applied - NHS England Digital

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 2026?

Picker

Unchanged for 2026

Unchanged

- Sample period (April – June 2026)
- Eligibility criteria
- ICD-10 or ICD-11 codes accepted
- Use of our secure sample checking platform for uploading patient sample list
- Fieldwork methodology for survey (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 in the patient list (Note: we won't be contacting patients by email)
- Trend data (we will be able to compare last six years)

Changed for 2026

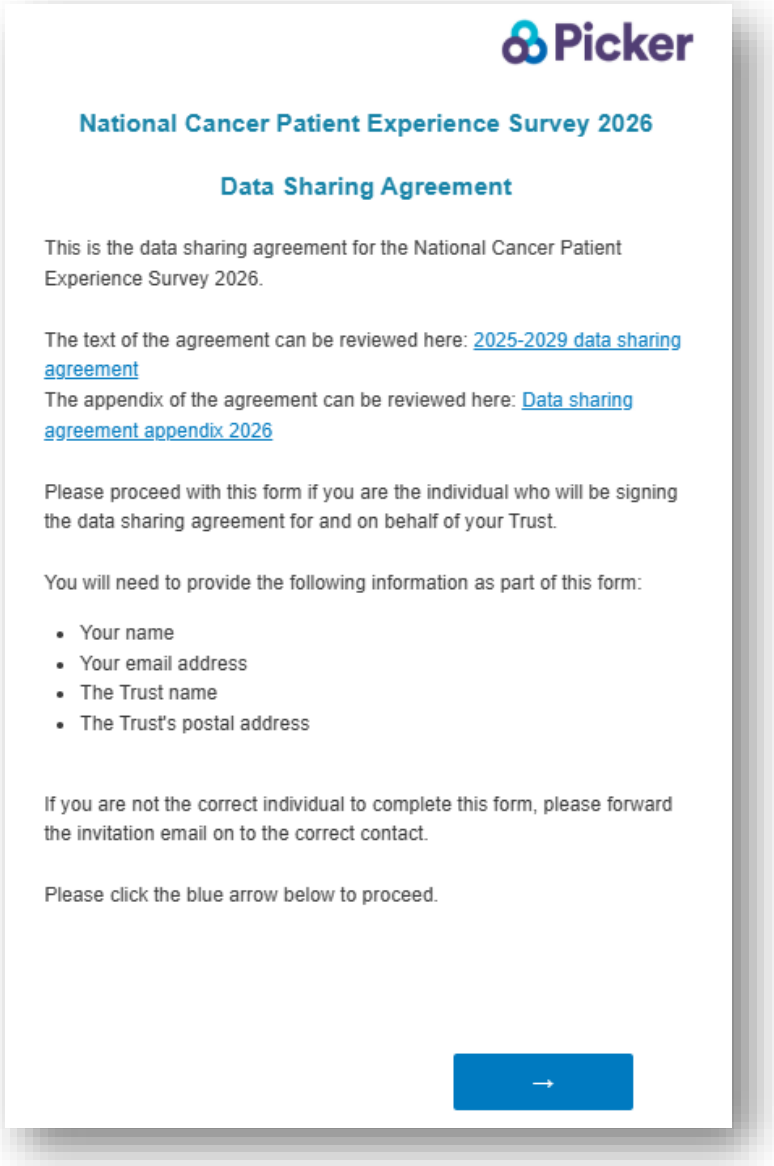
Changed for 2026: mobile data guidance

- Inclusion of mobile numbers are now mandatory. Additional checks will be used to check the accuracy of mobile numbers.
- You will include **valid mobile numbers and exclude landline numbers.** Valid mobile numbers should be either an 11-digit number starting with ‘07’ or a 12-digit number starting with ‘+44 7’.
- Eligible patients should be included in the sample whether or not they have a mobile phone number.
- DO NOT include patients' numbers for those who have explicitly dissented to the use of their mobile number
- DO NOT include patients’ numbers if there is a note specifying that the number belongs to someone other than the patient, such as a carer or family member. However, if the patient has provided a “work mobile” for their records this is fine to include, and if nothing is specified alongside the number it’s fine to assume this belongs to the patient.

Note: This is to ensure we better understand coverage of mobile number across trusts, we will not be contacting patients by text message for 2026.

Changed for 2026: Data Sharing agreement

- The Data Sharing Agreement (DSA) is now valid for the next 5 years 2025-2029. This must be signed by all trusts.
- Each year Picker will contact you to confirm the details remain valid.



Picker

National Cancer Patient Experience Survey 2026

Data Sharing Agreement

This is the data sharing agreement for the National Cancer Patient Experience Survey 2026.

The text of the agreement can be reviewed here: 2025-2029 data sharing agreement
The appendix of the agreement can be reviewed here: Data sharing agreement appendix 2026

Please proceed with this form if you are the individual who will be signing the data sharing agreement for and on behalf of your Trust.

You will need to provide the following information as part of this form:

- Your name
- Your email address
- The Trust name
- The Trust's postal address

If you are not the correct individual to complete this form, please forward the invitation email on to the correct contact.

Please click the blue arrow below to proceed.

→

Changed for 2026 - questionnaire

The questionnaire for 2026 will be published on the website in August at https://www.ncpes.co.uk/survey-instructions/. We are planning to make two small changes this year:

- **Q64** "Which of the following best describes you? Female; Male; Non-binary; Prefer to self-describe; Prefer not to say" – This question will likely be updated, the wording is TBC.
- **Q2:** We are planning to update the response options to align with Jess' Rule.

2025	2026
Before you were diagnosed, how many times did you speak to a healthcare professional at your GP practice about health problems caused by cancer? 1 Once 2 Twice **3 Three or four times** 4 Five or more times 5 Don't know / can't remember	Before you were diagnosed, how many times did you speak to a healthcare professional at your GP practice about health problems caused by cancer? 1 Once 2 Twice **3 Three times** **4 Four times** 5 Five or more times 6 Don't know / can't remember

Sampling process and support materials

Picker

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

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

Guidance materials

Survey materials

- Sampling Instructions
- The Survey Handbook
- The Patient List Template
- Declaration Form
- Platform User Guide

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

Guidance materials

Dissent posters

NHS

Help us improve cancer care for everyone

If you have had treatment at this NHS trust 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 2026 will be contacted to take part in a survey.

Taking part in the survey is **voluntary** and all answers are **confidential.**

If you are invited, we will use your personal details to send you a letter explaining how to take part. We may also send you a text message. We will only use your details to carry out a 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** want to take part, or have any questions about the survey, please contact this NHS trust by 28th July 2026: [space for trust to insert contact details, please include telephone number and email address]

For more information about the survey: www.ncpes.co.uk

If you do not want to take part, you will still need to contact us if you have a National Data Opt Out. The Department of Health and Social Care has confirmed that this survey is exempt. For more information: https://digital.nhs.uk/services/national-data-opt-out/programmes-to-which-the-national-data-opt-out-should-not-be-applied. Or scan the QR code.

The survey will be carried out by Picker on behalf of NHS England. The Secretary of State for Health and Social Care provided support for confidential patient information to be used to identify people diagnosed with cancer and invite them to take part in this survey. This is known as Section 251 support and was based on advice from an independent group, the Confidentiality Advisory Group, which includes members of the public.

Dissent posters (available in 11 languages) were sent out in March 2026.

It is a Section 251 requirement to display the poster during the sampling period of April, May, and June.

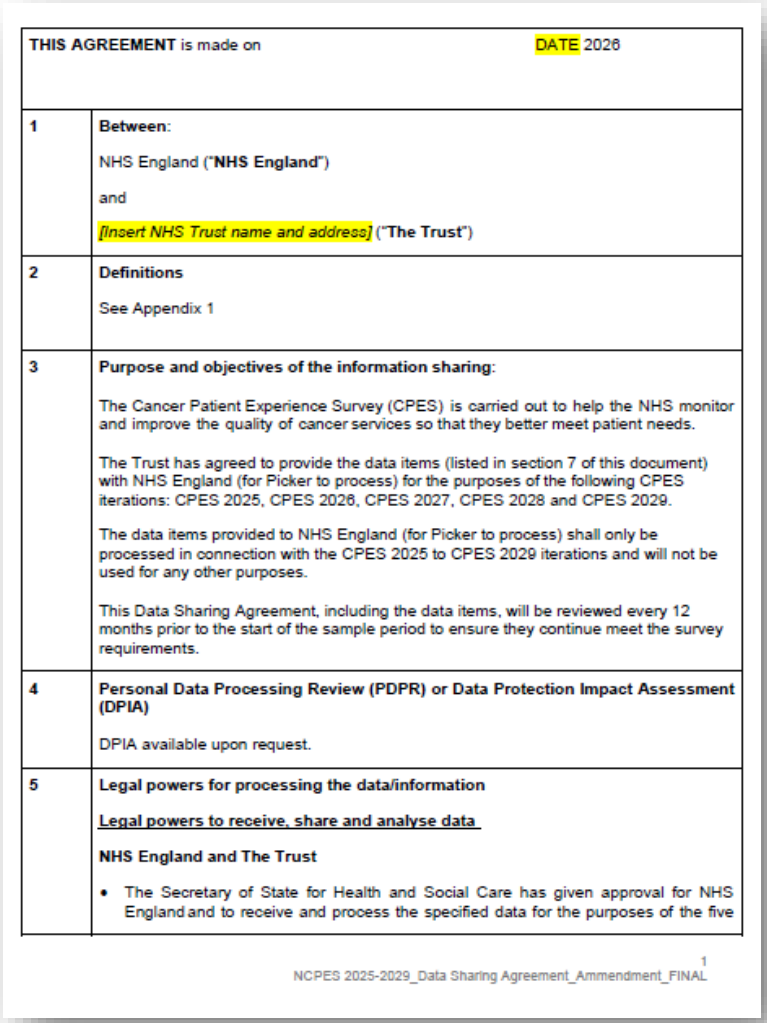
Patients will also have the opportunity to opt out through calling our helpline or sending back a blank questionnaire.

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

Data sharing agreement



THIS AGREEMENT is made on	DATE 2026
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 following CPES iterations: CPES 2025, CPES 2026, CPES 2027, CPES 2028 and CPES 2029. The data items provided to NHS England (for Picker to process) shall only be processed in connection with the CPES 2025 to CPES 2029 iterations and will not be used for any other purposes. This Data Sharing Agreement, including the data items, will be reviewed every 12 months prior to the start of the sample period to ensure they continue meet the survey requirements.
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 the five

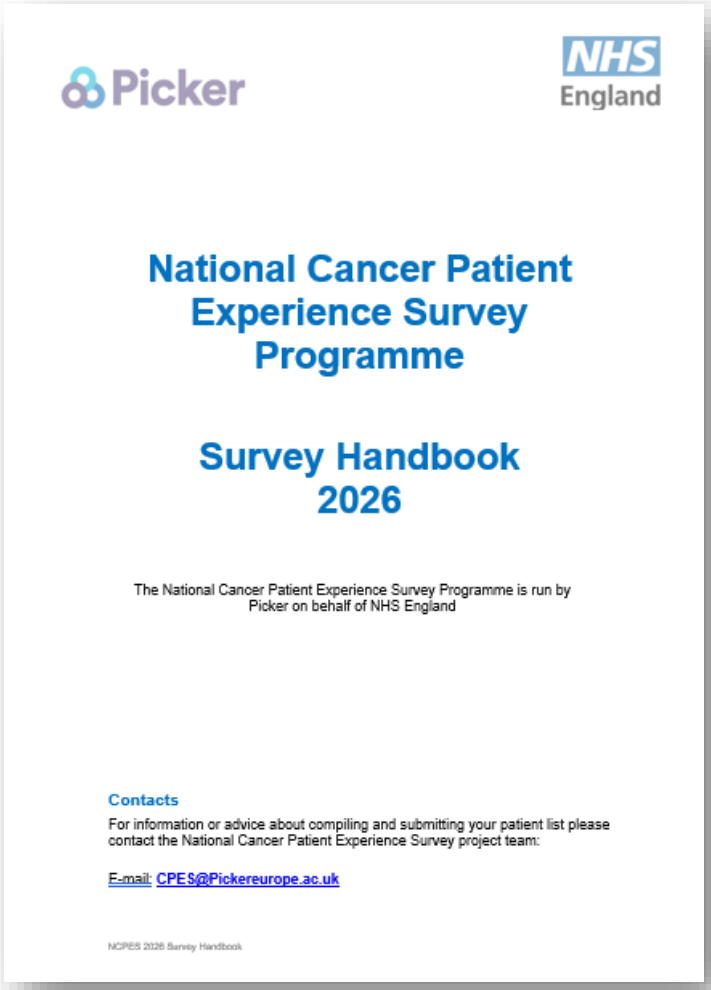
1
NCPES 2025-2029_Data Sharing Agreement_Ammendment_FINAL

This is largely unchanged as was multi-year agreement, with mobile numbers now being mandated for collection.

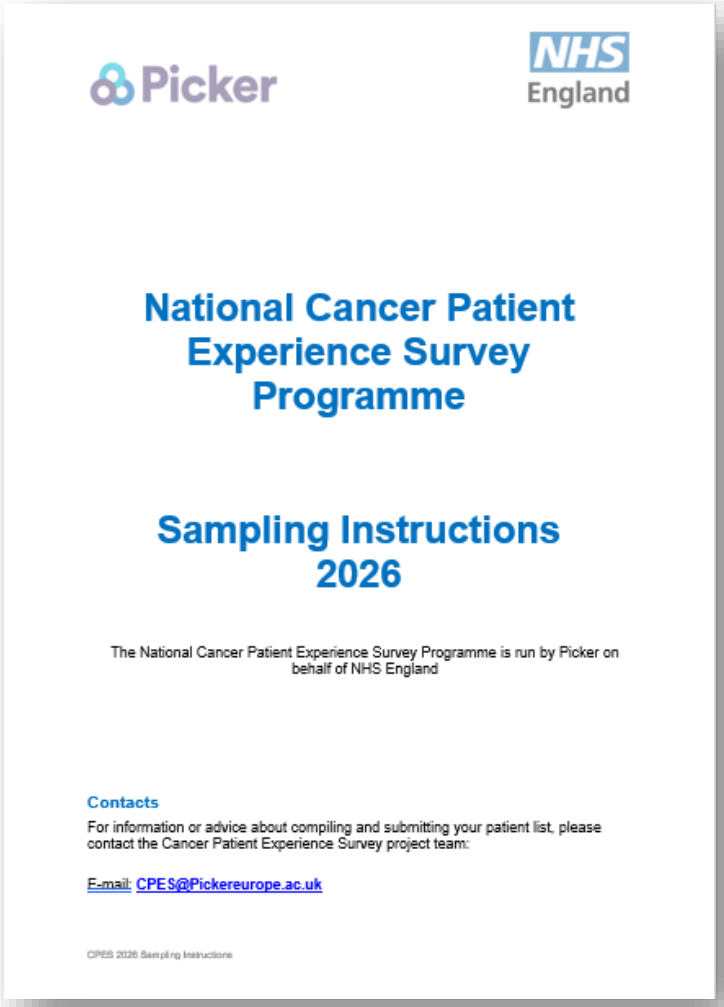
This has been sent out for re-signing, please return your response via Qualtrics this must be done before submitting your sample.

Guidance materials

Survey Handbook



Sampling Guidance



Guidance materials

Excel template

The ODS 3-digit code for your Trust, e.g. RA0	The unique serial number allocated to each patient by the trust (e.g. CPES26RTH0001). This is composed of the survey code (CPES26), 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

2026 National Cancer Patient Experience Survey: Sample Declaration Form

Picker

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:

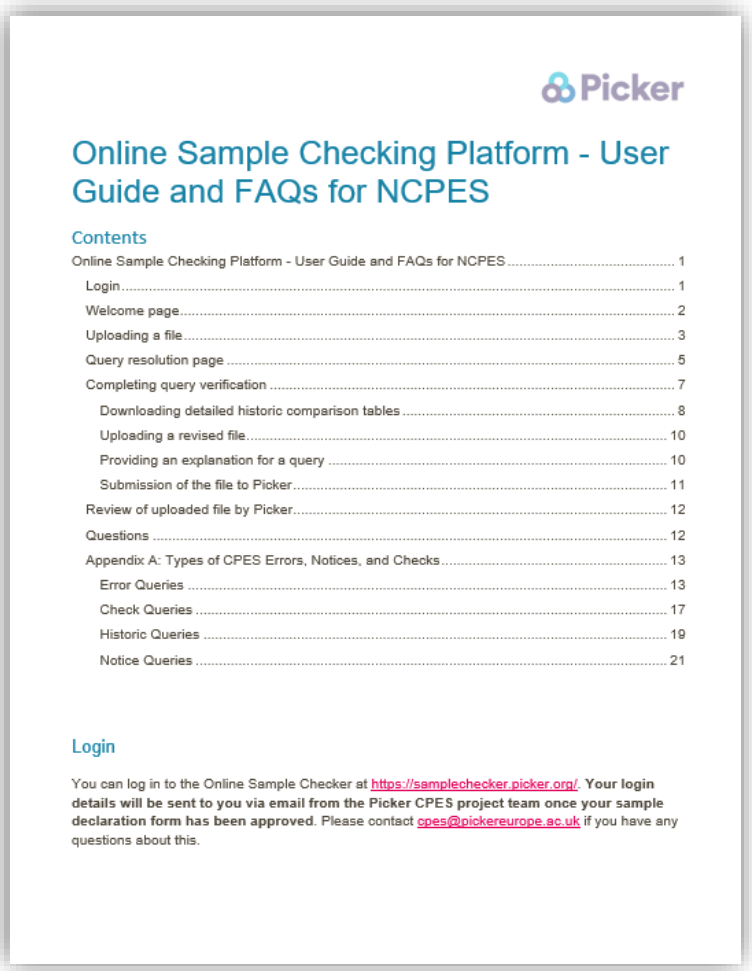
Comments box: There is a comments box at the top of the 'Checklist' tab for you to include any additional information regarding changes at your trust which may have affected the similarity of this year's patient list to last year's. This should include changes to services, mergers and / or acquisitions.

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 2026.		

Confirm that you have included:	Check	Comments
Patients with a **confirmed diagnosis of cancer.** That is, they do not have a holding code and they have been told they have cancer.		
Patients with an ICD-10 code of **C00-C43, C45-C83, C85-C99 and D05** or equivalent ICD-11 code (See Appendix A in the Sampling Instructions for more details) in their PAS record.		

Guidance materials

Sample checker user guide



Picker

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.

Your patient list

Picker

Eligibility criteria – Who to include

- Patients discharged between 01 April to 30 June 2026

- 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 (01 April to 30 June 2026)
- 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**:

- patients treated SOLELY as 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

Please ONLY exclude people if they do not meet the sampling criteria. Do not exclude for other reasons.

Cancer related treatment

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

- all forms of chemotherapy, radiotherapy, surgical resections, palliative surgery (debulking etc.)
- treatments for 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 **shouldn't** 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

- The survey sample does not include patients who were **seen solely as outpatients** for cancer related treatment.
- Over the last few years, we have explored ways to widen the scope of the sampling approach so that patients who solely have outpatient appointments could be included in the sample.
- After thoroughly exploring different approaches, such as inclusion of such patients in the list produced locally by Trusts and use of national datasets including cancer registration, we have not been able to find an approach that meets the criteria of being timely, accurate, consistent and low burden.
- More information about this is available on the NCPES website.

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

Picker

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/

Picker

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 for NCPES 2026.

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.

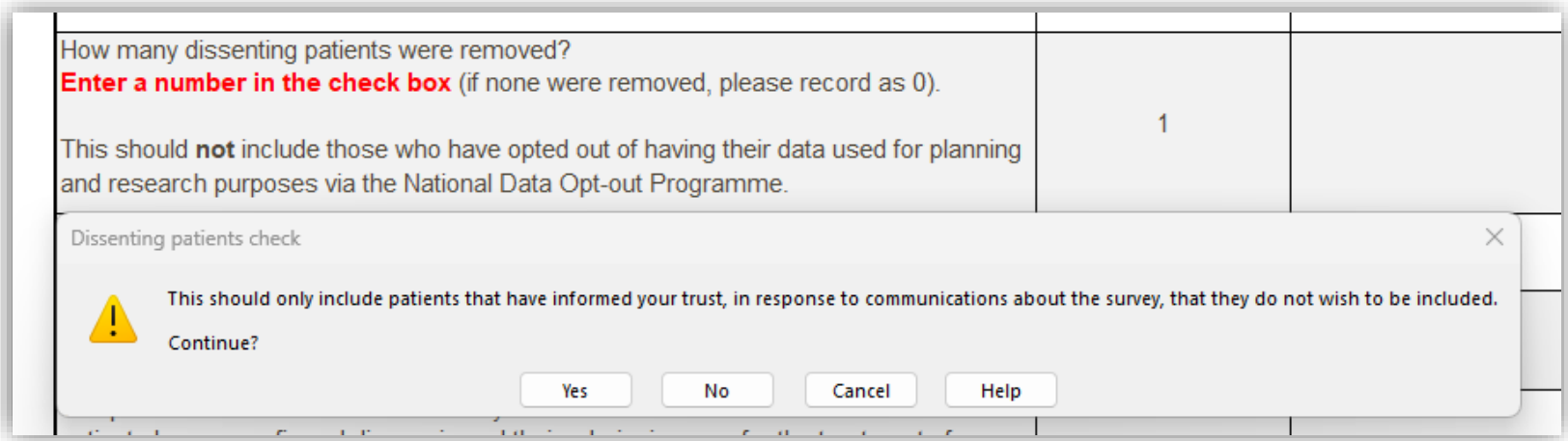
The member of staff responsible for compiling and checking the patient list must complete the Patient List Declaration Form and send to Picker before submitting their patient list.

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



Removals following validation

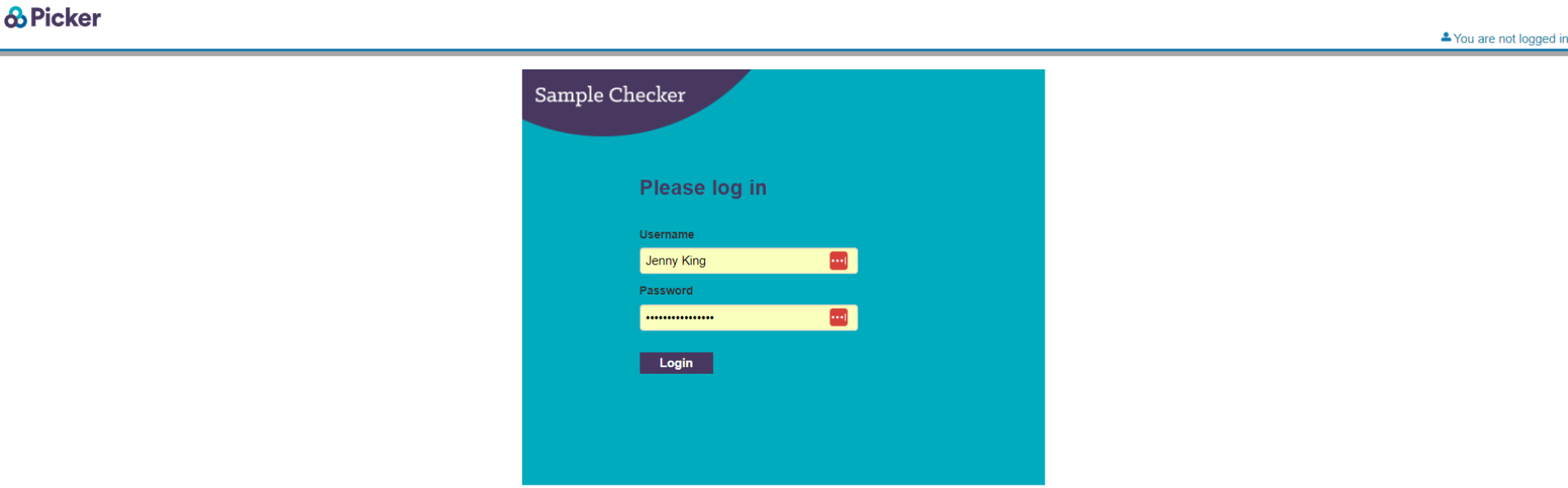
The patient list has been validated with your Cancer Services Team to ensure all patients have a confirmed diagnosis and their admission was for the treatment of cancer.		
How many patients were removed following validation from the Cancer Services Team? **Enter a number in the check box** (if none were removed, please record as 0). An approximate number is acceptable as this is being used for monitoring purposes only.		

Patient list template spreadsheet

	A	B	C	D	E	F	G	H	I	J	K	L
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. CPES26RTH0001). This is composed of the survey code (CPES26), 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 ar belonging that indivi Ensure as much as possible t this is populated will be us DBS chec
	Trust code	**Patient Record Number (PRN)**	**Title**	**Initials / First name**	**Surname**	**Address 1**	**Address 2**	**Address 3**	**Address 4**	**Address 5**	**Postcode**	**NHS numl**

Submitting your patient list

https://samplechecker.picker.org/

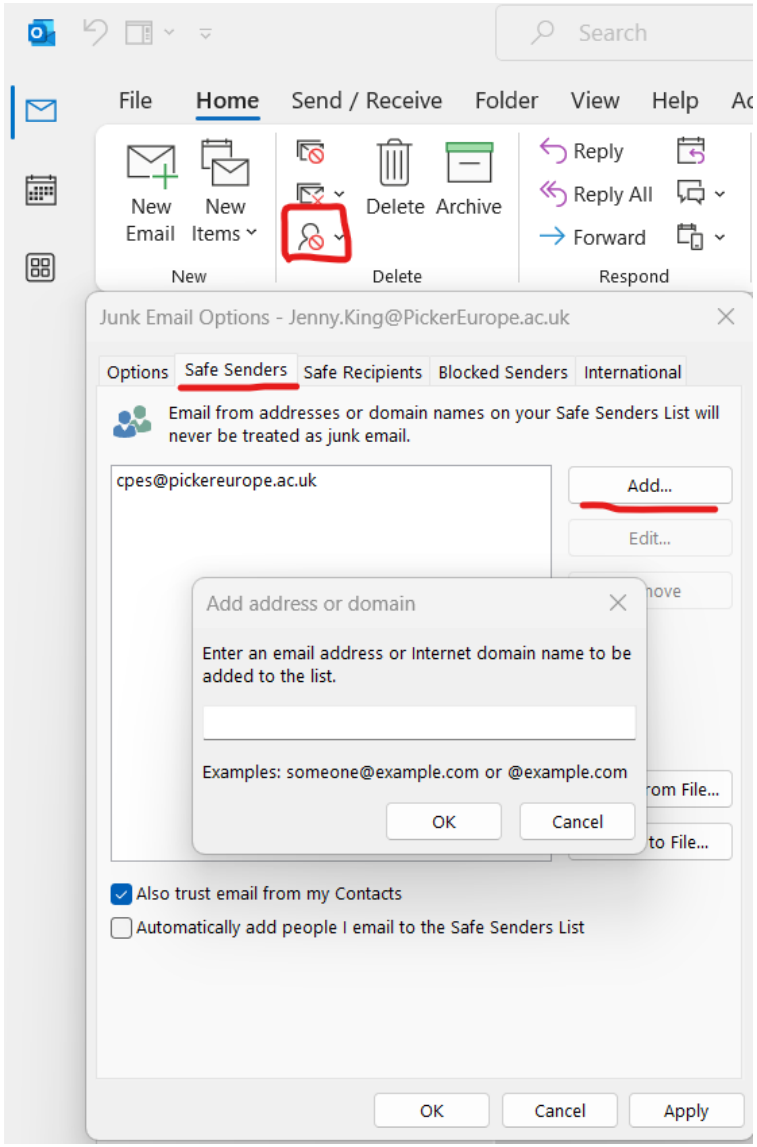


Submitting your patient list

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



- 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

Picker

Dates for submission and follow-up

NOTE: The dates have all shifted one week earlier compared to last year

31 Jul	• Deadline for trusts to submit data sharing agreements (DSAs)
31 Jul	• Deadline for trusts to confirm cover letter signatory information and trust logos
10 Aug	• **Trusts to start submitting patient sample declaration forms and lists to Picker**
26 Aug	• NHS England to contact all trusts that have not responded to Picker
04 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
14 Sep	• **All samples must be approved by this date for Picker to send out Mailing one**

We request early submission as sample approval can take a few weeks

Your role / Picker's role

Picker

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)

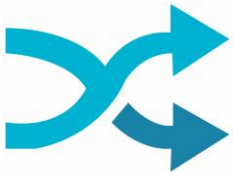
Data team members:

- 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:

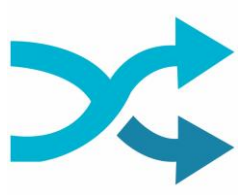
- Check the patient list before it is submitted to Picker to ensure that only patients are included who are aware of their diagnosis and have been treated by the cancer team
- During fieldwork – support Picker to investigate cases of ‘no cancer’

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

Picker

FAQ

Question	Answer
If patients opt-out nationally (to all patient experience surveys), does this apply to this survey?	The NCPES is **exempt** from the National Data Opt-Out Programme. 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 2026 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 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.

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FAQ

Question	Answer
Will you need Caldicott 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 and the transfer of data from your trust to Picker will be covered from the data sharing agreement.
Will we 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. Only patients specified in the guidance materials should be excluded from the patient list. 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.

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FAQ

Question	Answer
Why are patients with C44 and C84 ICD-10 codes excluded? Why are outpatients 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.
Should patients who were seen for diagnostic tests be included in the sample?	Please exclude patients who were only seen from 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 we will pick them up in some other 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 sampling. People receiving SACT as a day case or inpatient should be included.

FAQ

Question	Answer
Can we include people 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.
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?**	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.

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FAQ

Question	Answer
We don't have email address 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 will not be contacting patients by email in 2026.
We don't have phone numbers for everyone, is that ok?	Yes. Patients will not be contacted by text message for the 2026 survey. However, we continue to explore the feasibility of this and therefore ask that you please submit mobile numbers where available for patients. More detailed guidance on mobile number submission can be found in the sampling instructions available on the NCPES website.
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'.

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FAQ

Question	Answer
Are there provisions for people whose first language isn't English?	Patients have the option to complete the questionnaire using a translating service offered from our Freephone provider. The online survey is also available in three languages (Polish, Bengali and Punjabi). The new survey website has a translated section 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 follow up question in the questionnaire (yes to being sent a survey in the future about their health and health care) then they could be contacted with a follow up questionnaire from research organisations that have requested and been approved from 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 survey be published?	Publication is expected by summer 2027.
Should trusts include patients who cannot be traced against the national spine in the DBS checks?	Yes. Please include these patients and Picker will run a DBS check across the whole sample. Picker will remove any patients who could not be traced.

Any further questions?

Picker NCPES team email:

CPES@PickerEurope.ac.uk

Picker

Picker Institute Europe
Suite 6, Fountain House
1200 Parkway Court
John Smith Drive
Oxford OX4 2JY

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

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

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