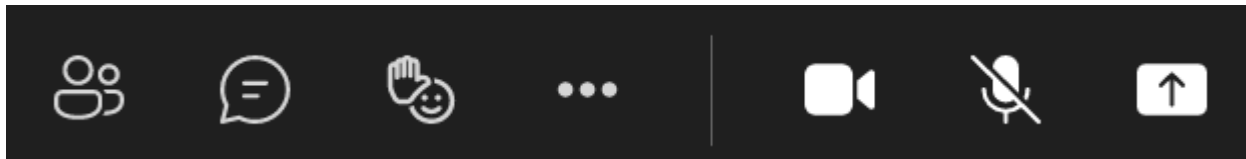# 2025 National Cancer Patient Experience Survey – sampling webinar for trusts

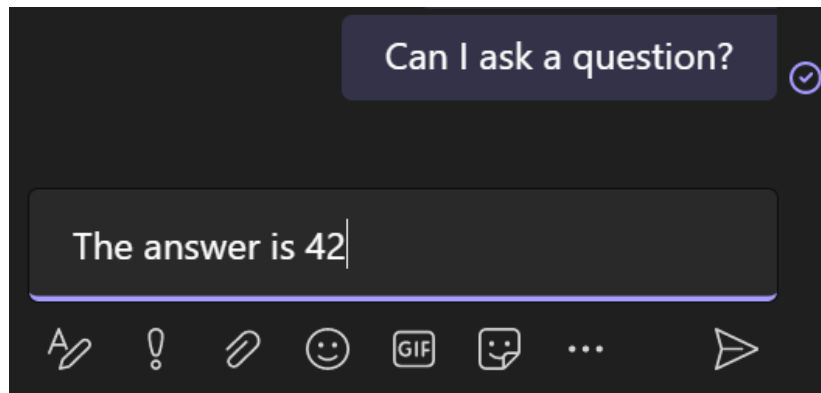## The presentation will start shortly!

Picker

Housekeeping

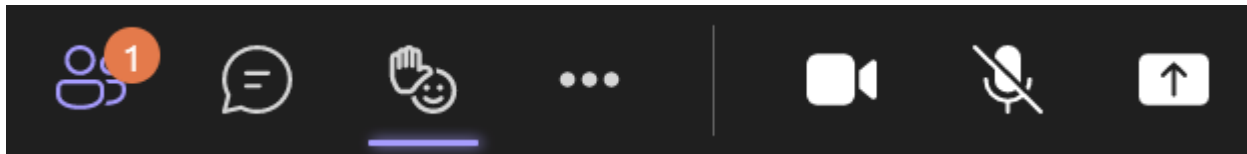- Keep yourself muted whilst the presentations are ongoing

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

- Add your thoughts/questions to the chat

- 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
- NCPES methodology pilot 2025
- What is the same and what has changed for 2025?
- 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

& Picker

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

- The 2021 survey saw the introduction of a redeveloped questionnaire

- 2025 will allow for five years of trend data for the majority of questions (comparisons between 2021 to 2025)

NCPES methodology pilot

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2025 NCPES Pilot

- We will be running a pilot in 2025 to evaluate the use of text reminders and a push to online responses

- Trusts taking part will have some different requirements for their sample
  - Sample period is from **March to June 2025**
  - Additional checks on mobile numbers in sample

All differences related to the pilot will be marked in purple throughout the presentation. If you are not taking part in the pilot, please ignore this information.

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Trusts taking part in the pilot

1	Airedale NHS Foundation Trust
2	Barking, Havering and Redbridge University Hospitals NHS Trust
3	Barnsley Hospital NHS Foundation Trust
4	Cambridge University Hospitals NHS Foundation Trust
5	Chelsea and Westminster Hospital NHS Foundation Trust
6	Chesterfield Royal Hospital NHS Foundation Trust
7	County Durham and Darlington NHS Foundation Trust
8	Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust
9	East Cheshire NHS Trust
10	Gateshead Health NHS Foundation Trust
11	George Eliot Hospital NHS Trust
12	Great Western Hospitals NHS Foundation Trust
13	Harrogate and District NHS Foundation Trust
14	King's College Hospital NHS Foundation Trust
15	Kingston Hospital NHS Foundation Trust

Trusts taking part in the pilot

16	Lewisham and Greenwich NHS Trust
17	Manchester University NHS Foundation Trust
18	Milton Keynes University Hospital NHS Foundation Trust
19	North Tees and Hartlepool NHS Foundation Trust
20	North West Anglia NHS Foundation Trust
21	Northern Care Alliance NHS Foundation Trust
22	Nottingham University Hospitals NHS Trust
23	Royal Cornwall Hospitals NHS Trust
24	Royal Devon University Healthcare NHS Foundation Trust
25	Royal Free London NHS Foundation Trust
26	Salisbury NHS Foundation Trust
27	Sheffield Teaching Hospitals NHS Foundation Trust
28	South Warwickshire University NHS Foundation Trust
29	St George's University Hospitals NHS Foundation Trust
30	Surrey and Sussex Healthcare NHS Trust

Picker

Trusts taking part in the pilot

31	The Dudley Group NHS Foundation Trust
32	The Hillingdon Hospitals NHS Foundation Trust
33	The Newcastle Upon Tyne Hospitals NHS Foundation Trust
34	The Princess Alexandra Hospital NHS Trust
35	The Royal Marsden NHS Foundation Trust
36	The Royal Orthopaedic Hospital NHS Foundation Trust
37	Torbay and South Devon NHS Foundation Trust
38	University College London Hospitals NHS Foundation Trust
39	University Hospital Southampton NHS Foundation Trust
40	University Hospitals Bristol and Weston NHS Foundation Trust
41	University Hospitals Coventry and Warwickshire NHS Trust
42	University Hospitals Dorset NHS Foundation Trust
43	University Hospitals Of North Midlands NHS Trust
44	University Hospitals Sussex NHS Foundation Trust
45	Worcestershire Acute Hospitals NHS Trust

Section 251

Picker

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. For both the main survey and pilot survey.

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
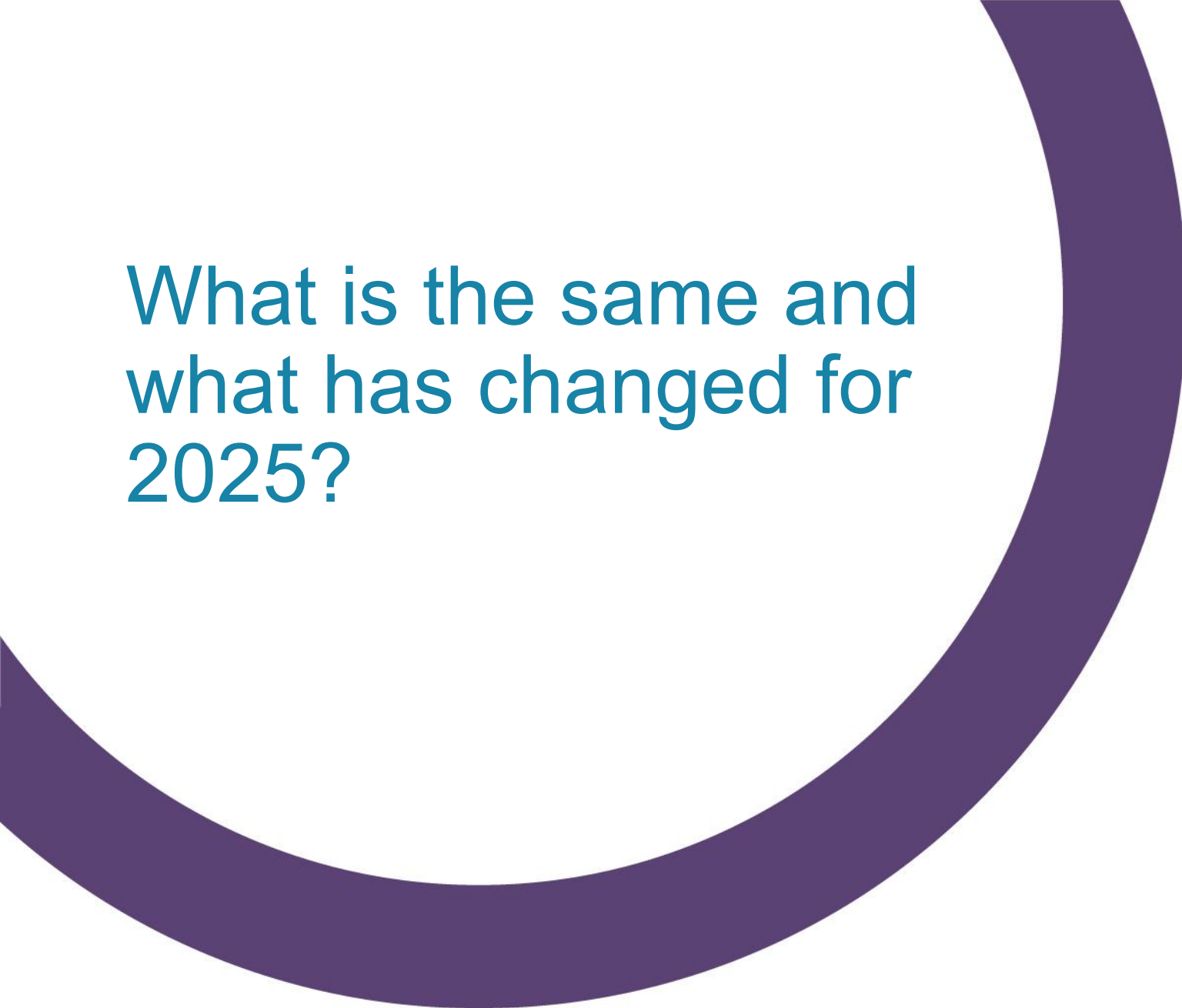
- Keep patient information confidential at all times and to comply with data protection legislation

- 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 2025?

Picker

Unchanged for 2025

Unchanged

- Sample period **main** survey (April – June 2025)

- Pilot information   **Pilot** sample period has different dates (March – June 2025).

- Eligibility criteria

- ICD-10 or ICD-11 codes accepted

- Use of our secure sample checking platform for uploading patient sample list

- Fieldwork methodology for **main** 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 and mobile phone numbers in the patient list (NOTE: we won't be contacting patients by text or email unless your trust is taking part in the pilot)

- Trend data (we will be able to compare 2021, 2022, 2023, 2024 and 2025 results)

Changed for 2025

Changed for 2025 - mobile data guidance

Information for all trusts (pilot and main)

- Eligible patients should be included in the sample whether or not they have a mobile phone number. The more data submitted as part of the sample the better we can understand potential methodology changes for the future.

- 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.

Pilot information

The inclusion of mobile numbers is important for trusts taking part in the pilot. Additional checks will be used to check the accuracy of mobile numbers. We ask that you 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'. However, if collating this data is causing delays in submitting your sample please **contact the team for advice on how to proceed.**

Mainstage info

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.**

Changed for 2025 – Data Sharing agreement

o The Data Sharing Agreement (DSA) is now valid for the next 5 years 2025-2029. This must be signed by all trusts.

o Each year Picker will contact you to confirm the details remain valid.

Pilot information

o There is an **additional** Data Sharing Agreement (DSA) that needs to be completed by trusts taking part in the survey pilot.

Picker

National Cancer Patient Experience Survey 2025

Data Sharing Agreement

This is the data sharing agreement for the National Cancer Patient Experience Survey 2025.

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 2025

Picker

National Cancer Patient Experience Pilot Survey 2025

Data Sharing Agreement

This is the data sharing agreement for the National Cancer Patient Experience Pilot Survey 2025.

The text of the agreement can be reviewed here: 2025 data sharing agreement pilot

The appendix of the agreement can be reviewed here: Data sharing agreement appendix 2025

Changed for 2025 - questionnaire

The questionnaire for 2025 can be found on the website - https://www.ncpes.co.uk/survey-instructions/. There have been a few small changes for this year…

The "**Other comments"** text at the end of the survey has been updated:

2024	2025
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.	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. The comments you provide in the boxes below will be shared with and 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 be shared with these organisations. NHS England will remove any information that could identify you before it publishes findings based on any of your feedback.

Changed for 2025 - questionnaire

Care from your GP Practice

Question 51 has updated wording of the question and some response options to improve clarity

2024

Care from your GP practice

51 Did you get the right amount of support from staff at your GP practice while you were having cancer treatment?

1. Yes, definitely
2. Yes, to some extent
3. No
4. My GP practice wasn't involved
5. Don't know / can't remember

2025

Care from your GP practice

51 Since your cancer diagnosis, have you had the help or support you needed from your GP practice?

1. Yes, definitely
2. Yes, to some extent
3. No, and I needed help or support
4. I have not needed any help or support from my GP practice
5. Don't know / can't remember

Changed for 2025 - questionnaire

Care from your GP Practice

Question 52 the wording of question and response options has been updated to improve clarity. Introductory text explaining providing context needed to answer the next question has been added.

As part of your care, you might be offered a cancer care review by your GP practice. This involves a conversation with someone from your GP practice about how your cancer diagnosis and treatment affected your health and well-being. It is also an opportunity for you to talk about any concerns you have and ask for any information, support or care you need.

52 Have you had a review of your cancer care by a member of staff at your GP practice?

1 ☐ Yes

2 ☐ No

3 ☐ Don't know / can't remember

52 Since your cancer diagnosis, have you had a cancer care review with someone from your GP practice about any concerns you have or any information, support or care you need?

1 ☐ Yes

2 ☐ No, and I was diagnosed **less than or around** 12 months ago

3 ☐ No, and I was diagnosed **more than** 12 months ago

4 ☐ Don't know / can't remember

Changed for 2025 - questionnaire

Question 69 has been removed from the survey that will be used in the <u>pilot</u>. This is because the pilot participants are sampled from March (rather than the usual months of April to June) and would therefore not be included in the re-contact database.

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

1 ☐ Yes, and I understand that this does NOT mean that I would have to take part in any future surveys or research

2 ☐ No, I would prefer not to be contacted again

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

Guidance materials

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

2 sets of materials available - one version for main survey and another one for pilot

Survey instructions

Find documents and materials related to conducting the survey.

Survey Materials

2025 CPES Main Survey Instructions →

2025 Pilot Survey Instructions →

Pilot information

Ensure you use the "2025 Pilot Survey Instructions" if you are taking part in the pilot. These documents will cover both pilot requirements (March sample) and main requirements (April to June sample).

Guidance materials

main survey materials

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

Pilot survey materials

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

Guidance materials

Dissent posters

Dissent posters (available in 11 languages) were sent out in March 2025.

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

Pilot information
Trusts taking part in the pilot display poster during sampling period of March, 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

Data sharing agreement

Guidance materials

Survey Handbook

Pilot information

Pilot Survey Handbook
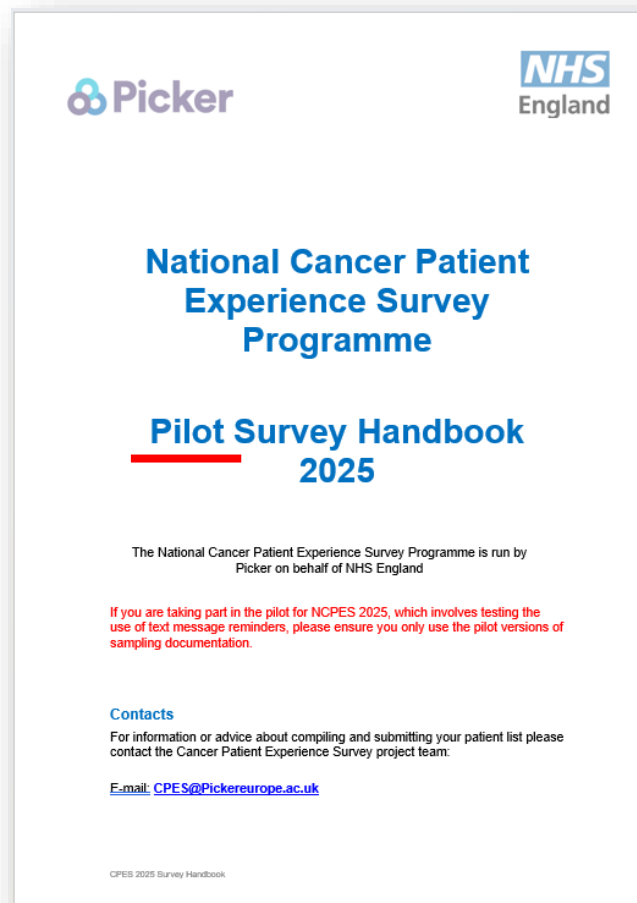
Guidance materials

Sampling Guidance
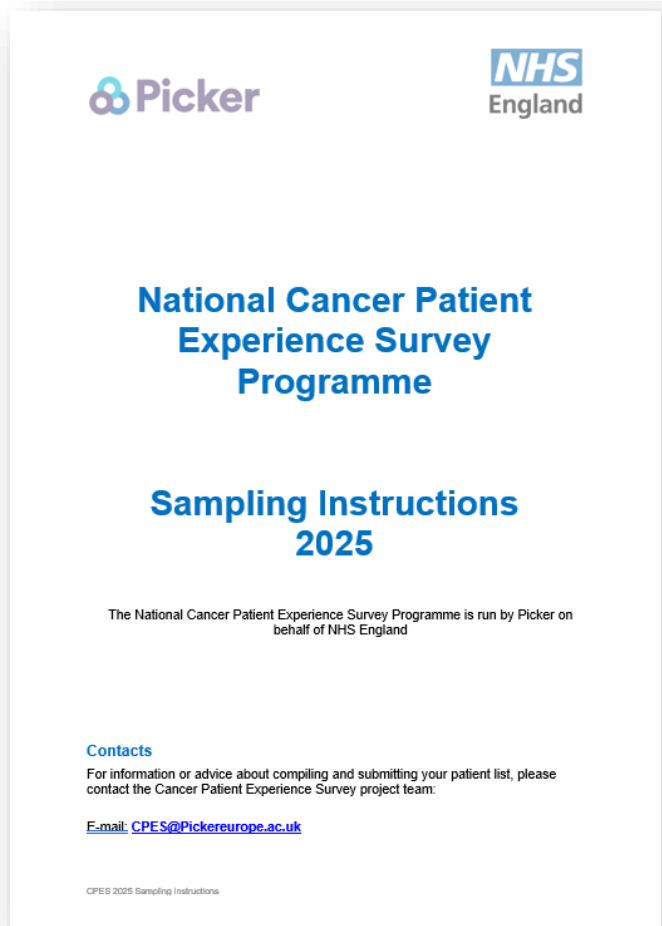
Pilot Sampling Guidance
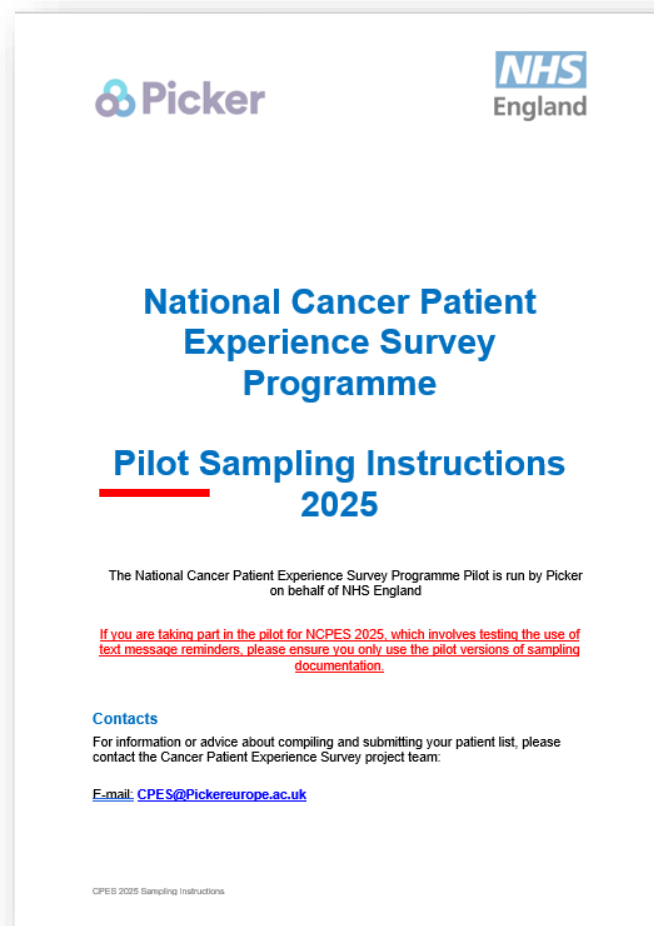
Guidance materials

Excel template

Trust code	Patient Record Number (PRN)	Title	Initials / First name	Surname
The ODS 3-digit code for your Trust, e.g. RA0	The unique serial number allocated to each patient by the trust (e.g. CPES25RTH0001). 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

Excel template

P	Q	R	S	T
Day of Admission	Month of Admission	Year of Admission	Day of Discharge	Month of Discharge
Day of admission (1 or 2 digits; e.g. 7 or 26)	1 = January 2 = February 3 = March 4 = April 5 = May 6 = June 7 = July 8 = August 9 = September 10 = October 11 = November 12 = December	Year of admission (4 digits; e.g. 2025)	Day of discharge (1 or 2 digits; e.g. 2 or 30)	3 = March 4 = April 5 = May 6 = June

Guidance materials

Declaration form

2025 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 2025.		

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.		

Declaration form

2025 National Cancer Patient Experience Survey: Sample Declaration Form

Picker

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If you are taking part in the pilot for NCPES 2025, which involves testing the use of text message reminders, please ensure you only use the pilot versions of sampling documentation.

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

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 March, April, May, or June 2025. As your trust is taking part in the pilot, the list should include discharges from March, in addition to the usual months of April, May and June 2025.		

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.		

Guidance materials

Pilot information

Sample checker user guide

Sample checker user guide

Online Sample Checking Platform - User Guide and FAQs for NCPES

& Picker

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.

Online Sample Checking Platform - User Guide and FAQs for NCPES

& Picker

Contents

If you are taking part in the pilot for NCPES 2025, which involves testing the use of text message reminders, please ensure you only use the pilot versions of sampling documentation.

Login

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Your patient list

&8 Picker

Eligibility criteria – Who to include ✔

- **Main survey:** Patients discharged between 1st April to 30th June 2025

- **Pilot:** Patients discharged between 1st March to 30th June 2025

- 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 (main survey 1st April to 30th June 2025)

- **Pilot information** (Pilot 1st March to 30th June 2025)

- 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

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 **<u>only</u>** includes eligible patients who have a **<u>confirmed</u>** diagnosis of cancer whose admission during the sampling period was **<u>in relation</u>** 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 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?

    [Yes]   [No]   [Cancel]   [Help]

NEW: 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 for main survey

	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. CPES25RTH0001). 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.	G 1 2 9 0
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	G
3														
4														

Patient list template spreadsheet for pilot survey

T	U	V	W	X	Y	Z	AA	AB	AC	AD
3 = March 4 = April 5 = May 6 = June	Year of discharge (4 digits; e.g. 2025)	4-7 digits, include sub-categories for these codes, i.e. 2A01.2. DO NOT include 2C3Z, 2B01, 2B02, 2A90.C, 2A90.A, 2A90.B, 2B0Z, 2B2Z	3-4 digits, include sub-categories for these codes, i.e. C25.1. These should be between C00 & C97 and D05 codes. DO NOT include C44 codes and C84 codes.	Code in the form NNN as specified by NHS Digital	The 3-5 character Sub ICB Location code which will be billed for the care of the patient	The type of admission; 1 = ordinary admission (inpatient), 2 = day case admission, 3 = regular day case admission & 4 = regular night admission	Record the hospital organisation code where the patient was treated as specified by NHS Digital	Record the hospital site name where the patient was treated if the site code is unavailable	Please include where available	Please include valid UK mobile numbers. These should be either an 11-digit number starting with '07' or a 12-digit number starting with '+44 7'. DO NOT include landline numbers.
Month of Discharge	Year of Discharge	ICD-11 Chapter Code (if these are available)	ICD-10 Chapter Code (only complete if your trust has not updated to ICD-11 codes)	Main specialty	Sub ICB Location code	Patient classification	Site code	Site name	Patient email address	Patient mobile phone number

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

  Pilot information Historic difference will be calculated to take March discharges into account.

- **Notice** – provides an overview of the information in the sample, no action needed

Safe Sender List
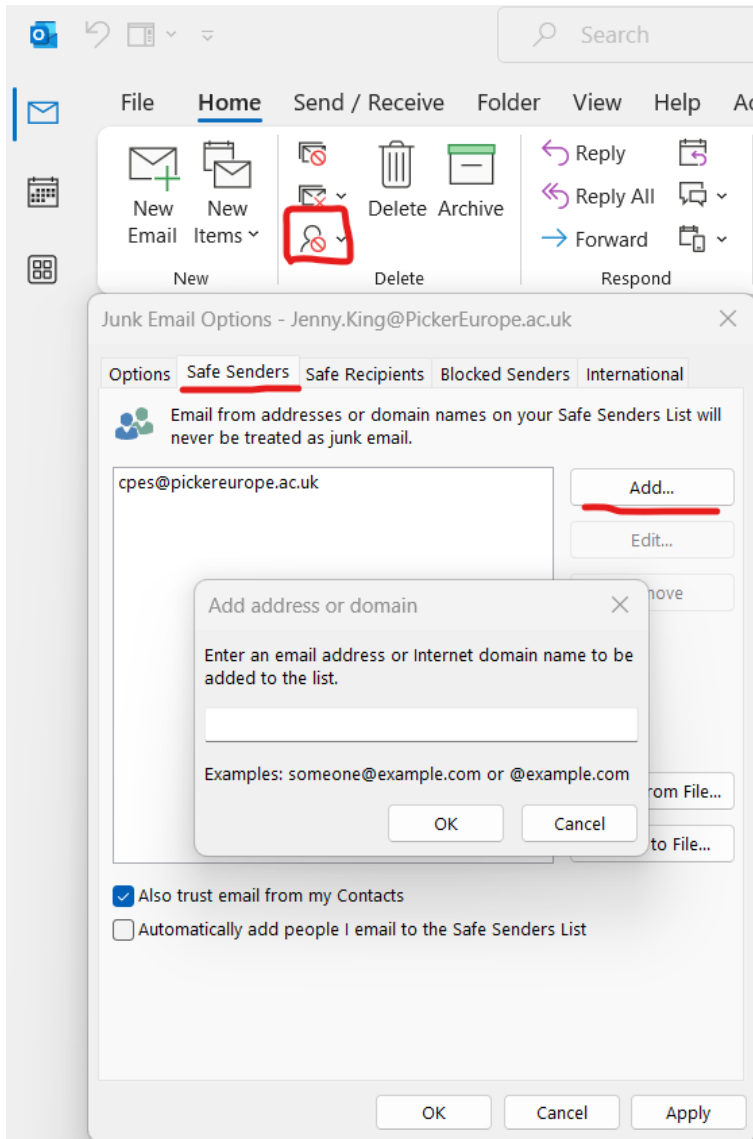
- Remember to add the Picker email address to your safe sender list!

- 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

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Dates for submission and follow-up for main survey and the pilot†

01-Aug	• Deadline for trusts to submit data sharing agreements (DSAs)
01-Aug	• Deadline for trusts to confirm cover letter signatory information and trust logos
18-Aug	• Trusts to start submitting patient sample declaration forms and lists to Picker
5-Sep	• NHS England to contact all trusts that have not responded to Picker
12-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
17-Sep	• All samples must be approved by this date for Picker to send out mailing one

†Note: Although final submission deadline is 17 Sept, we encourage submission early Sept 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'
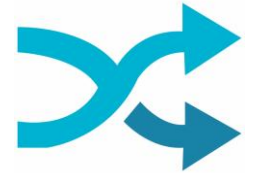
Picker's role

- 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
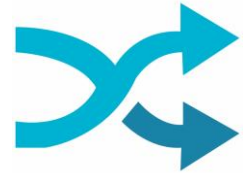
Picker's role

- 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

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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 2025 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.

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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.

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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 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 patients in the NCPES sample who do have this information. If you are taking part in the **pilot,** please still provide the data you do have.
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.

Pilot information

Please <u>do not</u> include land line numbers

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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 Q69 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 early summer 2026.

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FAQ

Question	Answer
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.
Will the pilot participants receive a different survey? Will the pilot results be published?	For patients in the pilot a different questionnaire will be used, though the only difference is that Q69 (the re-contact question) has been removed. The pilot results will not be combined with the main survey in the published results. However, survey responses and free text comments from those in the pilot will be shared with each individual NHS trust.
For individuals in the pilot (March discharges), do trusts need to exclude landlines from March to June or only March?	If possible, please exclude from March to June. If this is a lot of additional work and causing a delay in your sample submission please contact Picker.

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Any further questions?

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