

National Cancer Patient Experience Survey Programme

Survey Handbook 2020

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1 Introduction

NHS England and NHS Improvement are hosting the 2020 iteration of the National Cancer Patient Experience Survey (NCPES) on a voluntary basis during the spring of 2021.

The survey supports the implementation of [Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020](#). The strategy highlights that improving people's experience across the pathway needs to be prioritised and recommends that NCPES should continue to evolve and be repeated every year.

The survey is overseen by an advisory group which consists of patients, professionals, voluntary sector representatives, academics and patient survey experts.

Aside from the national importance of this survey, there are important direct benefits for your trust in taking part:

- You will receive a bespoke report on your cancer patients' experiences (where 20 or more responses are received), broken down by cancer type grouping.
- The results will help you meet the requirement to measure patient experience as set out in the Peer Review Measures for Cancer.
- The results will help you to populate your Quality Accounts.

2 Survey Information

2.1 Who is carrying out the survey?

The survey is being carried out by Picker on behalf of NHS England and NHS Improvement.

2.2 Who will be included in the survey?

The survey will cover acute and specialist NHS Trusts in England that provide adult cancer services.

All adult patients (aged 16 and over), with a **confirmed diagnosis of cancer**, who have been admitted to hospital as inpatients for **cancer related treatment**, or who were seen as day case patients for **cancer related treatment**, and have been discharged between 1st April 2020 and 30th June 2020 will be included in the survey.

2.3 What is the survey method?

The 2020 survey will replicate the 2019 survey methodology. The survey will be conducted by post, with two reminders (to non-responders only) as is the case with other national patient surveys. A standard questionnaire, covering letter and up to two reminder letters will be used. Patients will also be sent a link to complete the survey online should they prefer to do so.

A national Freephone helpline will be available for patients, and will support completion of the survey through phone and language translation facilities.

2.4 How much will it cost?

The costs of survey development, fieldwork, and reporting are being met by NHS England and NHS Improvement under the national contract with Picker. Trusts do not need to appoint a survey contractor.

2.5 Has the survey been reviewed by the Data Coordination Board?

The Data Coordination Board has reviewed and approved this survey.

2.6 Does the survey have Section 251 approval?

The application for Section 251 approval has been reviewed by the Confidentiality Advisory Group at the Health Research Authority and we are awaiting an outcome. This approval allows the common-law duty of confidentiality to be set aside and data to be transferred to Picker for the purpose of mailing out materials for the 2020 survey.

2.7 How will the survey findings be reported?

Individual trust reports (for those trusts participating) will be published on Picker's Cancer Patient Experience Survey website in the autumn of 2021. Due to the voluntary nature of the 2020 survey and the fact that not all trusts are participating, it may not be possible to produce CCG and Cancer Alliance reports. However, these will be produced where there is complete information available (i.e. where there is data available for all trusts who compose the CCG or Cancer Alliance).

Participating trusts will be provided with trust-level free-text analysis reports providing automated semantic and sentiment analysis of written comments received as part of the surveys. The reports are designed to:

- Take advantage of the growing preference for understanding and acting on free-text comments
- Provide essential feedback beyond the constraints of close ended questions
- Identify positive themes and areas of concern
- Analyse strength of feeling among patients
- Recommend areas for improvement, consolidation and retention
- Help present findings to drive engagement and change
- Track attitudes over time

The data will be used to inform the cancer dashboard, which is co-produced by NHS England and NHS Improvement and Public Health England, as a tool to help clinical leaders, commissioners and providers to quickly and easily identify priority areas for improvement in their cancer services. Please see www.cancerdata.nhs.uk/dashboard

Picker will assist any trust with the interpretation of its data, and will provide two virtual workshops for trusts to sign up. These will provide insight and action planning around how to make use of the results for service improvement.

3 Survey Responsibilities

3.1 What do trusts need to do?

3.1.1 Create a survey team

We recommend you set up a survey team to carry out all responsibilities. The best way to ensure that your survey is a success is to involve from the beginning those people who have the most impact on patients' experiences and who will be responsible for responding to the results of the survey. As a minimum, you will need a survey lead, a person from your data team who will draw your patient sample and a cancer specialist who will validate your patient list.

3.1.2 Advertise the survey and record dissenters

Trusts should have in place a system to inform patients about the upcoming survey with an option for them to opt out **if they wish not to be included in the survey**. For the 2020 survey, trusts were provided with posters, leaflets and website wording for display around relevant areas of the trust during the sampling window of April, May and June. This material provided space to add details of a nominated person within the trust that patients could contact, should they wish to opt out of the survey. We are aware that due to the circumstances at the time, some trusts were unable to display the posters. That does not stop the trust taking part in the survey because there are other ways for patients to opt out of the survey, and the cover letter will explain that to them.

Trusts should also have a way to **keep record of those who have opted out** so that these patients can be identified when compiling the patient list and subsequently removed from the eligible list of patients before it is submitted to Picker for approval.

The survey leads will need to work closely with the person who compiles the patient list, and check carefully that **all patients who have opted out are removed from the sample**. The patient list must be signed off by the trust's nominated survey lead before it is submitted to Picker.

3.1.3 Draw an accurate sample

Trusts' responsibilities are to ensure that the patient list is drawn accurately and in accordance with the Sampling Instructions. The Sampling Instructions are aligned as closely as possible to those used for the Care Quality Commission's annual Adult Inpatient Survey, which is already carried out by NHS Trust Information Systems staff.

3.1.4 Provide a signature

Trusts should provide the signature they would like to include at the bottom of the covering letters sent to patients. This should be in a JPEG format. If you would also like to provide the trust logo, this should be submitted alongside the signature. Otherwise, a generic logo will be generated of your trust name to appear at the top of the covering letters. Trusts must ensure Picker receives this information **prior** to submitting the patient list, to ensure there are no delays in starting fieldwork.

3.1.5 Manage patient queries, as needed, during fieldwork

While Picker will be managing most of the queries that patients may have during fieldwork through a Freephone helpline and email address, Picker may need to consult trusts on any queries from patients regarding their diagnosis. Although careful checks carried out by a clinical cancer team member before the patient sample list is submitted to Picker are intended to remove any patients who may not be aware of their diagnosis, some patients may still have queries or may not have understood their diagnosis clearly.

In addition, although Picker will be conducting deceased checks prior to each mailing, tracing services are not fool-proof and some patients may die before the questionnaire is delivered. Whilst we expect that most reports of deceased patients who are missed through DBS checks will be reported to Picker directly, either through the survey email or the Freephone helpline, your trust may be contacted by a bereaved relative and special sensitivity will be required when responding to them. **If you do have such contact please inform Picker immediately to ensure that no further mailings are sent to the deceased patient.**

3.2 What will Picker do?

All other survey work will be carried out by Picker. This will include postage, data entry and the production of reports.

Picker will also undertake all deceased checks. The DBS checks will be undertaken at least three times during the fieldwork period: before initial send out; and before each of the two reminders. Picker guarantees that the send out of the initial mailing and the reminders will take place within 48 hours of the relevant DBS deceased check for your trust being received from the service. This arrangement will make the process more efficient and will ensure that the number of deceased patients in the sample will be minimised. It will also reduce the amount of work that trust staff have to undertake.

4 Key dates for the 2020 survey

4.1 Time table

The key dates for the 2020 survey are listed in table 1. Trusts should ensure all tasks expected from them are completed to the dates given to reduce the risk of delaying the survey allowing Picker to publish data as soon as feasible after the conclusion of fieldwork.

Table 1: Key dates for the 2020 survey

Dates	Task	Responsibility
8 th February 2021	Deadline for informing Picker of key trust contacts (e.g. survey lead, data team member, clinical cancer team member)	Trusts
9 th February 2021	Webinar 1 for trusts – covering data protection, sampling instructions, common errors and helpful tips	Picker to lead; Trusts to attend
15 th February 2021	Deadline for trust survey leads (or other applicable staff) to submit data sharing agreements. Note: must be received before patient list is submitted	Trusts
15 th February 2021	Patient list submission start date – date for trusts to aim towards	Trusts
8 th March 2021	Last day for submitting patient list to Picker (trusts should aim to submit by late February)	Trusts
12 th March 2021	Deadline for patient list approval (can take 2-3 weeks, please aim to submit early)	Trusts/Picker
6 th April 2021	Mailing 1	Picker
27 th April 2021	Mailing 2	Picker
18 th May 2021	Mailing 3	Picker
18 th June 2021	End of fieldwork	Picker

4.2 Patient list submission and follow-up timings

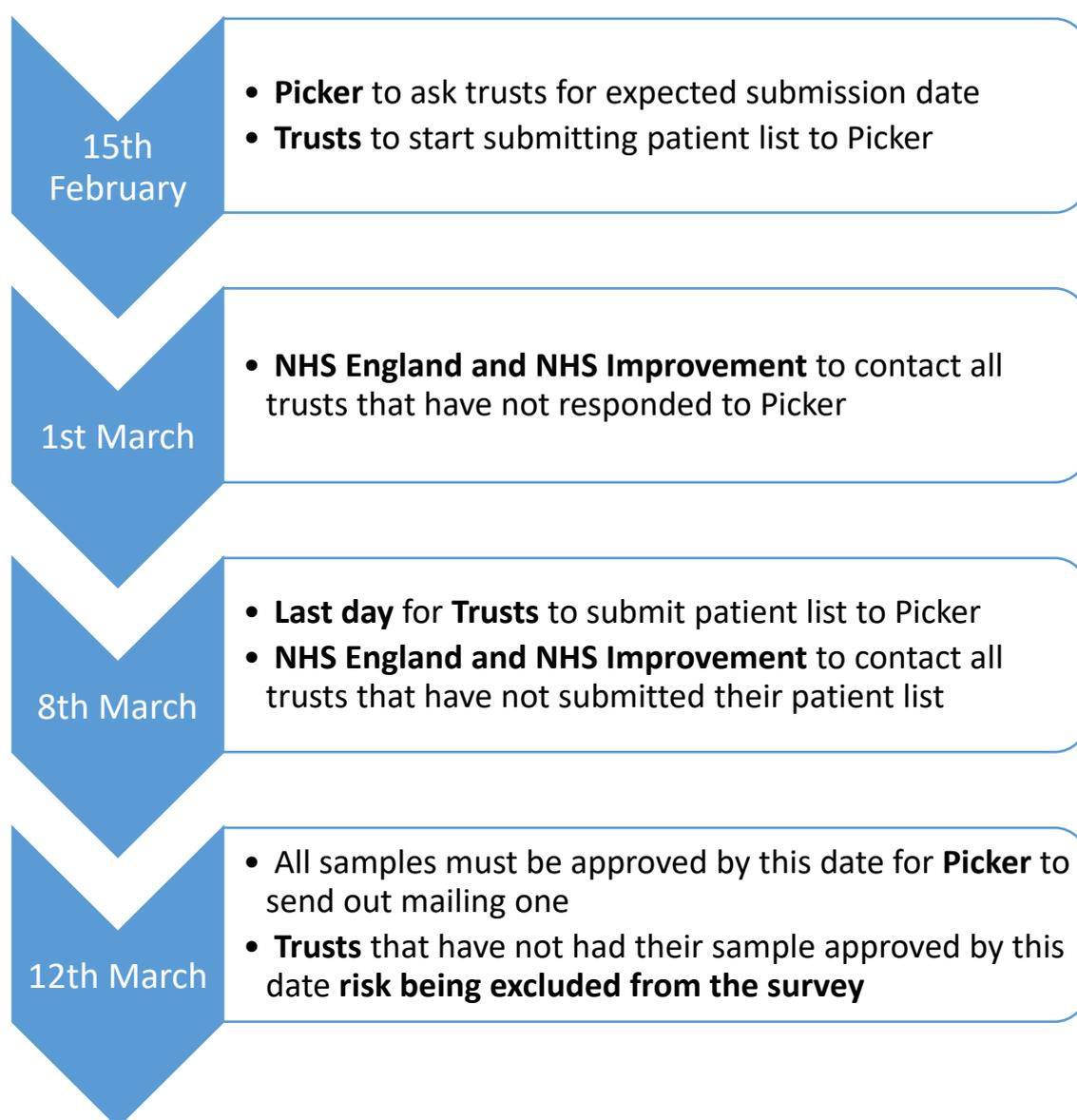
Picker are happy to support you and work with you through any sampling issues and queries you may have during the sampling period (starting 15th February

2020). Please do not hesitate to contact us if you should have any questions in the meantime. If there are any foreseen issues or delays in submitting your patient list, please contact us immediately.

Submission: It is imperative for you to submit your patient list as early as possible, ideally by late February. Approval can take 2-3 weeks due to sample queries and/or resubmissions. Submitting early will ensure your trust can receive approval in time to be included in this year's survey.

Patient list queries: It is equally important to respond swiftly to any queries Picker raises regarding your submitted patient list. Picker will follow up on any unresolved queries within two working days. If queries are still unresolved after two further working days, NHS England and NHS Improvement will be contacting the survey lead.

Figure 1. Submission and Follow-up process



5 Data Protection and Confidentiality

5.1 Principles of data protection

When carrying out the survey, both Picker and NHS Trusts need to ensure that they comply with the Data Protection Legislation (this refers to the DPA 2018 and the General Data Protection Regulation (GDPR)). Trusts will also need to comply with the NHS Code of Practice on Confidentiality (2003), which incorporates the Caldicott Principles.

The guidelines in the Sampling Instructions will help to ensure that data are handled in a manner in keeping with the spirit of the Data Protection Act 2018, the General Data Protection Regulation, and the Market Research Society's Guidelines for social research (2005). It will be necessary to establish appropriate data security arrangements with Picker, who will send each trust a Data Security Agreement governing the transfer of personal data.

To find out more information about data protection, please visit the Information Commissioner's Office (ICO) website here: <https://ico.org.uk/>

For further guidance on adhering to GDPR, see the Market Research Society website here: <https://www.mrs.org.uk/standards/gdprsupport>

5.2 Internet transfer of encrypted data

Trusts may send their patient list to Picker over the internet using Picker's secure sample checking platform. This is to ensure a high level of security and to protect against any accidental or intentional interception during the transfer of patients' details. This platform will also conduct a number of automatic checks on the patient list, thereby reducing the time spent signing off the sample. Picker will provide guidance on the use of this platform to trusts.

The trusts are the owners of the data, so the transfer of patient data is ultimately the trust's decision, because the trust remains legally responsible for the security and processing of the information it shares.

5.3 Using the online sample checking platform

You may already have an account to access the Picker's secure online sample checking platform; if not then you will shortly receive an e-mail with your access details.

1. Go to the Picker's secure upload website at <https://samplechecker.picker.org/>.
2. Login to your account using the account details provided.
3. Full upload instructions will be sent to you by email. Please follow those detailed instructions carefully.

If you have any problems, please contact the Picker CPES team at CPES@pickereurope.ac.uk.

5.4 Data Security Agreement

A Data Security Agreement will be sent digitally to the designated survey lead in each trust and will need to be signed by the trust. This agreement is based on the agreement used for the National Patient Survey Programme. By signing this agreement, Picker is obliged to keep the information confidential at all times, and to comply with current data protection legislation. It provides the trust with some recourse if a data protection breach was to occur as a result of any actions of Picker. The agreement also ensures that Picker staff members sign and abide by the agreement, which describes how patients' personal data will be sent to Picker, how the data will be stored and how it can be accessed and used.

5.5 National Data Guardian Review and patient opt outs

In July 2016 the National Data Guardian (NDG) Review on data security, consent and opt-outs was published. In July 2017 the Department of Health published "Your Data: Better Security, Better Choice, Better Care", the government's response to the NDG review. The review noted that further work was required before a decision could be made as to how the opt-out should be applied to surveys.

The Department of Health and Social Care has confirmed that the NCPES is exempt from the national data opt-out. Therefore, NDG opt outs **should not** be applied to the NCPES 2020 and you must not exclude patients on this basis. This means that **patients do not have to actively consent to their data being used for the purpose of this survey**; however as mentioned above, if patients choose to specifically opt-out of the 2020 NCPES their wishes should be respected.