

National Cancer Patient Experience Survey 2020

Technical Documentation

November 2021

Contents

Introduction	3
Scoring	3
Positive, negative and neutral scores.....	3
Adjusted response rate.....	3
Suppression	4
Question-level suppression.....	4
Double suppression	4
Comparisons between 2020 and 2019, and trend comparisons (2016-2020)	5
Introduction.....	5
How to interpret the results	5
Methodology	5
Confidence intervals.....	5
Introduction.....	5
How to interpret the results	5
Methodology	6
Respondent burden calculation	6
Further information	7
Appendix A.....	8
Appendix B.....	18
Appendix C.....	21

Introduction

This document sets out the methodology used in the analysis of the response data to the 2020 National Cancer Patient Experience Survey (CPES) and gives guidance on how to interpret the results. This includes the following:

- how percentage scores have been derived for each scored question
- rules on suppression and where it was applied
- methods for establishing differences between different groups of respondents
- methods for establishing changes from 2020 and 2019 and overall changes (2016 to 2020)
- how statistical confidence intervals around scores have been calculated

All of the results are available at <https://www.ncpes.co.uk/current-results>.

Scoring

Scores are presented for 52 questions that relate directly to patient experience. For all but one question (Q61), scores are presented as the percentage of positive responses out of all scored responses. For Q61, respondents rate their overall care on a scale of 0 to 10, of which the average was calculated for this question's presented score.

Positive, negative and neutral scores

For each scored question, each response option has been identified as either a positive, negative or neutral response. Scores were calculated using the total number of positive responses as the numerator and the total number of positive and negative responses as the denominator. Neutral scores (e.g. 'Don't know / can't remember') were excluded from this calculation.

See [Appendix A](#) for the mapping of positive, negative and neutral scores for all questions.

Adjusted response rate

During fieldwork for the 2020 survey, all patients were coded with an outcome code depending on their response to being sent the questionnaire. The outcome codes were as follows:

- Outcome 1a = patient completed the paper questionnaire
- Outcome 1b = patient completed the online questionnaire
- Outcome 1c = patient completed the questionnaire in English by phone
- Outcome 1d = patient used Language Line to complete the questionnaire with a translator in a language other than English
- Outcome 2 = questionnaire was returned undelivered (i.e. patient did not receive the questionnaire)
- Outcome 3 = patient deceased after the sample was drawn (i.e. patient may not have received the questionnaire)
- Outcome 4 = patient opted out of the survey (i.e. called the helpline, emailed or returned a blank questionnaire)

- Outcome 5 = patient is ineligible for the survey (i.e. patient was sampled incorrectly and does not meet the eligibility criteria for the survey)
- Outcome 6 = unknown (i.e. there has been no response from the patient)

To calculate the adjusted response rate, the numerator was the total number of patients with an outcome of '1a', '1b', '1c', and '1d.' The denominator was the total number of patients with an outcome of '1a', '1b', '1c', '1d', '4', and '6'. Therefore, patients that may not have received a questionnaire or were not eligible to take part were excluded from this calculation.

Suppression

After consultation with the Cancer Patient Experience Survey Advisory Group in April 2021 a decision was made to lower the question-level suppression and double suppression from <21 to <11 for CPES20 and future iterations of the survey. Agreement was also made to remove the response level suppression rule.

Where scores for 2016 to 2019 are shown these continue to use the question-level suppression of <21.

Question-level suppression

For 2020 scores, where the base size per question had <11 respondents, the score was suppressed and replaced with an asterisk (*). The base size did not include non-scored response options. For unscored questions, any frequencies were suppressed when the base size per question was <11.

For 2016 to 2019 scores, where the base size per question had <21 respondents, the score was suppressed and replaced with an asterisk (*). The base size did not include non-scored response options. For unscored questions, any frequencies were suppressed when the base size per question was <21.

Double suppression

Results for any sub-group breakdown adhere to the same suppression level as the question-level suppression but have an additional double suppression rule. Where any of the groups within the sub-group breakdown had <11 respondents (or <21 for 2016 to 2019) then the figure for this particular group was suppressed and replaced with an asterisk (*). If there was only one group within the sub-group that had <11 respondents (or <21 for 2016 to 2019) and was therefore suppressed, the group with the next lowest number of respondents was also suppressed and replaced with an asterisk (*). This rule applies to scores and proportions.

Comparisons between 2020 and 2019, and trend comparisons (2016-2020)

Introduction

Where possible¹, the scores for each of the scored questions from the 2020 results were compared with those from the 2019 results to see if there were any significant differences. Comparisons were also made across the last 5 iterations of the survey (2016-2020) to see if there were any trends. Comparisons were made at the trust level for each scored question. See [Appendix C](#) for a list of which questions were comparable to the previous year's scores.

How to interpret the results

In the Excel tables, results between 2020 and 2019 as well as trend results are marked with either '↑' or '↓' for a statistically significant increase or decrease, respectively.

Methodology

A longitudinal logistic regression model with robust variance estimation was used to determine whether there has been a significant change from the previous year and whether there are any trends over the last 5 years.² A linear regression was used to determine whether there are any changes to Q61 (overall experience question) from last year and for identifying any trends. Age, IMD quintile, ethnicity and tumour type are added as covariates since these variables may differ across years. Results were considered significant at the 99% ($p < 0.01$) level.

Confidence intervals

Introduction

The single percentage figures given as a score for each organisation for each question are an estimate of the score from the population, based on the responses received. Assuming the sample is representative of the organisation, confidence intervals are a method of describing the uncertainty around these estimates. The most common methodology, which was used here, is to produce and report 95 percent confidence intervals around the results. At the 95 percent confidence level the confidence intervals are expected to contain the true value 95 percent of the time (i.e. out of 100 such intervals, 95 will include the true figure).

How to interpret the results

The following example shows the unadjusted score for an organisation with 500 respondents to Q7 in the questionnaire, which asks about the explanation of test results. In this case, the unadjusted score is 83% and the confidence interval is calculated as between 79% and 86%.

¹ For the 2020 survey, 66 questions were comparable to 2019. For the trend comparisons, 48 questions were comparable across 2016-2020.

² In a small number of cases, data conditions (primarily small numbers of responses) did not permit the regression model to converge on an estimate of the year to year effect. In these cases, the significance test was omitted.

Question	Question text	Number of responses	Unadjusted score	95% Confidence Intervals	
				Lower	Upper
Q7	Were the results of the test explained in a way you could understand?	500	83%	79%	86%

Methodology

Confidence intervals for unadjusted scores for all questions (aside from Q61) were calculated using Wilson’s Confidence Intervals. This particular approach was chosen as it is more robust for small numbers (both numerators and denominators), and for results close to 0% or 100%. For Q61, confidence intervals are +/- 1.96 standard errors, which was calculated by:

$$S.E. = \frac{\sigma}{\sqrt{N}}$$

Where σ is the standard deviation of responses for that particular organisation.

For Q61, +/- 1.96 standard errors was used again, derived as a by-product of the regression routine itself.

Respondent burden calculation

The National Cancer Patient Experience Survey (CPES) complies with the Code of Practice for Statistics. Within the code, Practice V5.5 requires producers of statistics to monitor the burden on respondents providing their information. In order to achieve this, the following calculation is done for CPES:

Number of respondents x Average time spent completing the survey

Limiting the time frame to just those individuals who started and finished the survey on the same date, the average completion time is 23 minutes. (This is then 98.1% of all online respondents or 3,109 respondents).

If you then take out anyone who took over 100 minutes to complete (and assume they completed in multiple sittings within one day), the average is then 22 minutes. (This is then 97.1% of all online respondents or 3077 respondents).

Therefore, respondent burden calculated results for the 2020 CPES are:

3,077 respondents x 22 minutes = 1,136 hours spent completing the survey

Further information

For further information on the methodology and details of the statistical analysis, please contact CPES@PickerEurope.ac.uk

Appendix A

This table lists all questions, excluding the last section (about you) in the questionnaire. The questions were recoded into binary variables where 1 meant positive experience and 0 meant negative experience. The proportion of positive responses to negative responses were then used to calculate unadjusted and adjusted scores. The last column of this table indicates 'Yes' for response options that were used within the response-level suppression rule and 'No' if it was excluded from this suppression rule.

Question	Question text	Answer option	Option text	Scoring	Used in suppression
Q1	How long was it from the time you first thought something might be wrong with you until you first contacted your GP practice to talk about it?	1	Not applicable - I didn't contact my GP practice	n/a	Yes
		2	Not applicable - The GP first identified that something could be wrong	n/a	Yes
		3	Less than 3 months	n/a	Yes
		4	3-6 months	n/a	Yes
		5	6-12 months	n/a	Yes
		6	More than 12 months	n/a	Yes
		7	Don't know / can't remember	n/a	No
Q2	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	1	It was as soon as I thought was necessary	1	Yes
		2	It should have been a bit sooner	0	Yes
		3	It should have been a lot sooner	0	Yes
Q3	How many times did you speak to a healthcare professional at your GP practice about health problems caused by cancer?	1	Once	1	Yes
		2	Twice	1	Yes
		3	Three or four times	0	Yes
		4	Five or more times	0	Yes
		5	Don't know / can't remember	n/a	No
Q4	In the last 12 months have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?	1	Yes	n/a	Yes
		2	No	n/a	Yes
Q5	Beforehand, did you have all the information you needed about your test?	1	Yes	1	Yes
		2	No, I would have liked more information	0	Yes
		3	No, I did not need any information	n/a	No

Question	Question text	Answer option	Option text	Scoring	Used in suppression
		4	Don't know / can't remember	n/a	No
Q6	Overall, how did you feel about the length of time you had to wait for your test to be done?	1	It was about right	1	Yes
		2	It was a little too long	0	Yes
		3	It was much too long	0	Yes
		4	Don't know / can't remember	n/a	No
Q7	Were the results of the test explained in a way you could understand?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No, I did not understand the explanation	0	Yes
		4	I did not have an explanation but would have liked one	0	Yes
		5	I did not need an explanation	n/a	No
		6	Don't know / can't remember	n/a	No
Q8	How long ago were you told that you had cancer?	1	Before January 2020	n/a	Yes
		2	Between January 2020 and March 2020	n/a	Yes
		3	After March 2020	n/a	Yes
		4	Don't know / can't remember	n/a	No
Q9	Who told you that you had cancer? (Cross ALL that apply)	1	A specialist doctor or consultant at hospital	n/a	Yes
		2	My GP	n/a	Yes
		3	A Clinical Nurse Specialist (CNS)	n/a	Yes
		4	Someone else	n/a	Yes
		5	Don't know / can't remember	n/a	No
Q10	When you were first told that you had cancer, had you been given the option of having a family member, carer or friend with you while being told?	1	Yes, I was told I could bring someone to the face to face appointment	1	Yes
		2	Yes, I was told I could have someone on the telephone or video call with me	1	Yes
		3	No, I had an appointment or call but I was not told I could have someone with me	0	Yes
		4	No, I was told by letter or email	0	Yes
		5	Don't know / can't remember	n/a	No
Q11	How do you feel about the way you were told you had cancer?	1	It was done sensitively	1	Yes
		2	It should have been done a bit more sensitively	0	Yes
		3	It should have been done a lot more sensitively	0	Yes

Question	Question text	Answer option	Option text	Scoring	Used in suppression
Q12	Did you understand the explanation of what was wrong with you?	1	Yes, I completely understood it	1	Yes
		2	Yes, I understood some of it	0	Yes
		3	No, I did not understand it	0	Yes
		4	Don't know / can't remember	n/a	No
Q13	When you were told you had cancer, did you receive written information about the type of cancer you had?	1	Yes, and it was easy to understand	1	Yes
		2	Yes, but it was difficult to understand	0	Yes
		3	No, I did not receive written information about the type of cancer I had	0	Yes
		4	I did not need written information	n/a	No
		5	Don't know / can't remember	n/a	No
Q14	Before your cancer treatment started, were your treatment options explained to you?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	There was only one type of treatment that was suitable for me	n/a	Yes
		5	Don't know / can't remember	n/a	No
Q15	Were the possible side effects of treatment(s) explained in a way you could understand?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No, side effects were not explained	0	Yes
		4	I did not need an explanation	n/a	No
		5	Don't know / can't remember	n/a	No
Q16	Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No, I was not offered any practical advice or support	0	Yes
		4	Don't know / can't remember	n/a	No
Q17	Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No, future side effects were not explained	0	Yes
		4	I did not need an explanation	n/a	No
		5	Don't know / can't remember	n/a	No
Q18	Were you involved as much as you wanted	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes

Question	Question text	Answer option	Option text	Scoring	Used in suppression
	to be in decisions about your care and treatment?	3	No	0	Yes
Q19	Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	1	Yes	1	Yes
		2	No	0	Yes
		3	Don't know / can't remember	n/a	No
Q20	How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	1	Very easy	1	Yes
		2	Quite easy	1	Yes
		3	Neither easy nor difficult	0	Yes
		4	Quite difficult	0	Yes
		5	Very difficult	0	Yes
		6	I have not tried to contact my Clinical Nurse Specialist	n/a	No
Q21	When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	1	All or most of the time	1	Yes
		2	Some of the time	0	Yes
		3	Rarely or never	0	Yes
		4	I have not asked any questions	n/a	No
Q22	Did hospital staff give you information about support or self-help groups for people with cancer?	1	Yes	1	Yes
		2	No, but I would have liked information	0	Yes
		3	It was not necessary	n/a	No
		4	Don't know / can't remember	n/a	No
Q23	Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?	1	Yes	1	Yes
		2	No, but I would have liked a discussion or information	0	Yes
		3	It was not necessary / relevant to me	n/a	No
		4	Don't know / can't remember	n/a	No
Q24	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	1	Yes	1	Yes
		2	No, but I would have liked information	0	Yes
		3	It was not necessary	n/a	No
		4	Don't know / can't remember	n/a	No
Q25	Did hospital staff tell you that you could get free prescriptions?	1	Yes	1	Yes
		2	No, but I would have liked information	0	Yes

Question	Question text	Answer option	Option text	Scoring	Used in suppression
		3	It was not necessary	n/a	No
		4	Don't know / can't remember	n/a	No
Q26	During the last 12 months, have you had an operation (such as removal of a tumour or lump) at one of the hospitals named in the covering letter?	1	Yes	n/a	Yes
		2	No	n/a	Yes
Q27	Beforehand, did you have all the information you needed about your operation?	1	Yes	1	Yes
		2	No, I would have liked more information	0	Yes
		3	Don't know / can't remember	n/a	No
Q28	After the operation, did a member of staff explain how it had gone in a way you could understand?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No, but I would have liked an explanation	0	Yes
		4	I did not need an explanation	n/a	No
Q29	During the last 12 months, have you stayed overnight for cancer care at one of the hospitals named in the covering letter?	1	Yes	n/a	Yes
		2	No	n/a	Yes
Q30	Did hospital staff talk in front of you as if you weren't there?	1	Yes, often	0	Yes
		2	Yes, sometimes	0	Yes
		3	No	1	Yes
Q31	Did you have confidence and trust in the doctors treating you?	1	Yes, in all of them	1	Yes
		2	Yes, in some of them	0	Yes
		3	No, in none of them	0	Yes
Q32	If your family or someone else close to you wanted to talk to someone in the team looking after you during your stay in hospital, were they able to?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	My family or friends were not involved	n/a	No
		5	My family or friends did not want to talk to a member of the team	n/a	No
		6	I did not want my family or friends to talk to a member of the team	n/a	No
		7	Don't know / can't remember	n/a	No
Q33	Did you have confidence and trust	1	Yes, in all of them	1	Yes
		2	Yes, in some of them	0	Yes

Question	Question text	Answer option	Option text	Scoring	Used in suppression
	in the ward nurses treating you?	3	No, in none of them	0	Yes
Q34	In your opinion, were there enough nurses on duty to care for you in hospital?	1	There were always or nearly always enough on duty	1	Yes
		2	There were sometimes enough on duty	0	Yes
		3	There were rarely or never enough on duty	0	Yes
Q35	While you were in hospital did hospital staff ask you what name you prefer to be called by?	1	Yes, all of them did	1	Yes
		2	Only some of them did	0	Yes
		3	None of them did	0	Yes
Q36	Were you given enough privacy when discussing your condition or treatment?	1	Yes, always	1	Yes
		2	Yes, sometimes	0	Yes
		3	No	0	Yes
Q37	During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I had no worries or fears	n/a	No
Q38	Do you think the hospital staff did everything they could to help control your pain?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I did not have any pain	n/a	No
Q39	Overall, did you feel you were treated with respect and dignity while you were in the hospital?	1	Yes, always	1	Yes
		2	Yes, sometimes	0	Yes
		3	No	0	Yes
Q40	Did you receive clear written information about what you should or should not do after leaving hospital?	1	Yes	1	Yes
		2	No	0	Yes
		3	Don't know / can't remember	n/a	No
Q41	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	1	Yes	1	Yes
		2	No	0	Yes
		3	Don't know / can't remember	n/a	No
Q42		1	Yes	n/a	Yes

Question	Question text	Answer option	Option text	Scoring	Used in suppression
	During the last 12 months, have you been treated as an outpatient or day case for cancer care at one of the hospitals named in the covering letter?	2	No	n/a	Yes
Q43	While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I did not have any worries or fears	n/a	No
Q44	The last time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?	1	Yes	1	Yes
		2	No	0	Yes
		3	I didn't have an appointment with a cancer doctor	n/a	No
		4	Don't know / can't remember	n/a	No
Q45	During the last 12 months, have you had radiotherapy at any of the hospitals named in the covering letter?	1	Yes	n/a	Yes
		2	No	n/a	Yes
Q46	Beforehand, did you have all of the information you needed about your radiotherapy treatment?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I did not need any information	n/a	No
Q47	Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	It is too early to know if my radiotherapy is working	n/a	Yes
		5	I did not need any information	n/a	No
Q48		1	Yes	n/a	Yes

Question	Question text	Answer option	Option text	Scoring	Used in suppression
	During the last 12 months, have you had chemotherapy at any of the hospitals named in the covering letter?	2	No	n/a	Yes
Q49	Beforehand, did you have all of the information you needed about your chemotherapy treatment?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I did not need any information	n/a	No
Q50	Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	1	Yes, completely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	It is too early to know if my chemotherapy is working	n/a	Yes
		5	I did not need any information	n/a	No
Q51	Did the team looking after you give your family, or someone close to you, all the information they needed to help care for you at home?	1	Yes, they were given all the information they needed	1	Yes
		2	Yes, they were given some of the information they needed	0	Yes
		3	No	0	Yes
		4	Not applicable	n/a	No
		5	Don't know / can't remember	n/a	No
Q52	During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I did not need help from health or social services	n/a	No
		5	Don't know / can't remember	n/a	No
Q53	Once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No	0	Yes
		4	I did not need help from health or social services	n/a	No
		5	I am still having treatment	n/a	No
		6	Don't know / can't remember	n/a	No
Q54	As far as you know, was your GP given	1	Yes	1	Yes
		2	No	0	Yes

Question	Question text	Answer option	Option text	Scoring	Used in suppression
	enough information about your condition and the treatment you had at the hospital?	3	Don't know / can't remember	n/a	No
Q55	Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	1	Yes, definitely	1	Yes
		2	Yes, to some extent	0	Yes
		3	No, they could have done more	0	Yes
		4	My general practice was not involved	n/a	No
Q56	Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?	1	Yes, always	1	Yes
		2	Yes, some of the time	0	Yes
		3	No, never	0	Yes
		4	Don't know / can't remember	n/a	No
Q57	Have you been given a care plan? <i>A care plan is a document that sets out your needs and goals for caring for your cancer. It is an agreement or plan between you and your health professional to help meet those goals.</i>	1	Yes	1	Yes
		2	No	0	Yes
		3	I do not know / understand what a care plan is	n/a	No
		4	Don't know / can't remember	n/a	No
Q58	Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc.)?	1	Very good	1	Yes
		2	Good	1	Yes
		3	Neither good nor bad	0	Yes
		4	Quite bad	0	Yes
		5	Very bad	0	Yes
		6	Don't know / can't remember	n/a	No
Q59	Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	1	It was much too long	0	Yes
		2	It was a little too long	0	Yes
		3	It was about right	1	Yes
		4	Don't know / can't remember	n/a	No

Question	Question text	Answer option	Option text	Scoring	Used in suppression
Q60	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	1	Yes	1	Yes
		2	Yes, but I was not eligible to take part	1	Yes
		3	No	0	Yes
		4	No, but I would have liked them to	0	Yes
		5	Don't know / can't remember	n/a	No
Q61	Overall, how would you rate your care?	0		Average score is used	Yes
		1			Yes
		2			Yes
		3			Yes
		4			Yes
		5			Yes
		6			Yes
		7			Yes
		8			Yes
		9			Yes
		10			Yes
		not valid*		n/a	No

Appendix B

The table below shows the detailed mapping of 3-digit ICD codes to tumour groups. This has been used throughout the reporting of the 2020 results and is an identical mapping to previous years.

Tumour group	Cancer type (for case mix adjustment)	ICD code	Description
Brain / CNS	Brain	C71	Malignant neoplasm of brain
Breast	Breast	C50	Malignant neoplasm of breast
	DCIS	D05	Carcinoma in situ of breast
Colorectal / LGT	Rectal	C19, C20	Malignant neoplasm of recto-sigmoid junction (C19) and of rectum (C20)
	Colon	C18	Malignant neoplasm of colon
	Anal	C21	Malignant neoplasm of anus and anal canal (C21)
	Small intestine	C17	Malignant neoplasm of small intestine
Gynaecological	Ovarian	C56	Malignant neoplasm of ovary
	Endometrial	C54, C55	Malignant neoplasm of corpus uteri (C54) and of uterus, part unspecified (C55)
	Cervical	C53	Malignant neoplasm of cervix uteri
	Vulva / vaginal	C51, C52	Malignant neoplasm of vulva (C51) and vagina (C52)
Haematological	Non-Hodgkins lymphoma	C82, C83, C85	Follicular [nodular] non-Hodgkin's lymphoma (C82), diffuse non-Hodgkin's lymphoma (C83), other and unspecified types of non-Hodgkin's lymphoma (C85)
	Multiple myeloma	C90	Multiple myeloma and malignant plasma cell neoplasms
	Leukaemia	C91, C92, C93, C94, C95	Lymphoid (C91), myeloid (C92), monocytic (C93), and other leukaemia of specified (C94) and unspecified (C95) cell type
	Hodgkins lymphoma	C81	Hodgkin's disease

Tumour group	Cancer type (for case mix adjustment)	ICD code	Description
Head and Neck	Thyroid	C73	Malignant neoplasm of thyroid gland
	Laryngeal	C32	Malignant neoplasm of larynx
	Oropharyngeal	C01, C09, C10	Malignant neoplasm of base of tongue (C01), tonsil (C09) and oropharynx (C10)
	Oral	C02, C03, C04, C06	Malignant neoplasm of other / unspecified parts of tongue (C02), gum (C03), floor of mouth (C04) and other parts of mouth (C06)
	Parotid	C07, C08	Malignant neoplasm of parotid gland (C07) and other / unspecified major salivary gland (C08)
Lung	Lung	C33, C34	Malignant neoplasm of trachea (C33) and bronchus and lung (C34)
	Mesothelioma	C45	Mesothelioma
Prostate	Prostate	C61	Malignant neoplasm of prostate
Sarcoma	Soft tissue sarcoma	C46, C48, C49	Karposi's sarcoma (C46). Malignant neoplasm of retroperitoneum and peritoneum (C48) and other connective and soft tissue (C49)
	Bone sarcoma	C40, C41	Malignant neoplasm of bone and articular cartilage of limbs (C40) and of bones and articular cartilage of other and unspecified sites (C41)
Skin	Melanoma	C43	Malignant melanoma of skin
Upper Gastro	Oesophageal	C15	Malignant neoplasm of oesophagus
	Stomach	C16	Malignant neoplasm of stomach
	Pancreatic	C25	Malignant neoplasm of pancreas
	Liver	C22	Malignant neoplasm of liver and intrahepatic bile ducts
	Gall bladder	C23	Malignant neoplasm of gall bladder
Urological	Bladder	C67	Malignant neoplasm of bladder
	Renal	C64	Malignant neoplasm of kidney, except renal pelvis
	Penile	C60	Malignant neoplasm of penis
	Testicular	C62	Malignant neoplasm of testis
	Ureteric	C65, C66	Malignant neoplasm of renal pelvis (C65) and ureter (C66)

Tumour group	Cancer type (for case mix adjustment)	ICD code	Description
Other	Secondary	C77, C78, C79	Secondary and unspecified malignant neoplasm of lymph nodes (C77), of respiratory and digestive organs (C78) and of other and unspecified sites (C79)
	Any other		All other codes C00, C05, C11, C12, C13, C14, C24, C26, C30, C31, C37, C38, C39, C47, C57, C58, C63, C68, C69, C70, C72, C74, C75, C76, C80, C86, C88, C96, C97

Appendix C

This table lists all questions, excluding the last section (about you) in the questionnaire.

The questionnaire for the 2020 survey is based on the 2019 CPES questionnaire. There were some minor amendments made to reflect practice during the time that people were receiving treatment, to ensure that survey respondents could select the answers that were most relevant to them. Some questions with very minor changes are comparable to 2019. However these results should be interpreted with caution. Other questions are no longer comparable to 2019 due to the extent of the changes that had to be made.

Question	Question text	Change(s) made	Comparable to 2019
Q1	How long was it from the time you first thought something might be wrong with you until you first contacted your GP practice to talk about it?	Question text changed. Response options added. Response options changed.	No
Q2	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	Filter question changed (Q1).	Yes
Q3	How many times did you speak to a healthcare professional at your GP practice about health problems caused by cancer?	Question text changed. Response options changed. Filter question changed (Q1).	No
Q4	In the last 12 months have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?	Filter question changed (Q1).	Yes
Q5	Beforehand, did you have all the information you needed about your test?		Yes
Q6	Overall, how did you feel about the length of time you had to wait for your test to be done?		Yes

Question	Question text	Change(s) made	Comparable to 2019
Q7	Were the results of the test explained in a way you could understand?		Yes
Q8	How long ago were you told that you had cancer?	Response options changed to allow for future analysis.	No
Q9	Who told you that you had cancer? (Cross ALL that apply)		Yes
Q10	When you were first told that you had cancer, had you been given the option of having a family member, carer or friend with you while being told?	Question text changed. Response option added. Response options changed.	No
Q11	How do you feel about the way you were told you had cancer?		Yes
Q12	Did you understand the explanation of what was wrong with you?		Yes
Q13	When you were told you had cancer, did you receive written information about the type of cancer you had?	Question text changed. Response option changed.	Yes
Q14	Before your cancer treatment started, were your treatment options explained to you?		Yes
Q15	Were the possible side effects of treatment(s) explained in a way you could understand?		Yes

Question	Question text	Change(s) made	Comparable to 2019
Q16	Were you offered practical advice and support in dealing with the side effects of your treatment(s)?		Yes
Q17	Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?		Yes
Q18	Were you involved as much as you wanted to be in decisions about your care and treatment?		Yes
Q19	Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?		Yes
Q20	How easy or difficult has it been for you to contact your Clinical Nurse Specialist?		Yes
Q21	When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?		Yes
Q22	Did hospital staff give you information about support or self-help groups for people with cancer?		Yes
Q23	Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?		Yes
Q24	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?		Yes
Q25	Did hospital staff tell you that you could get free prescriptions?		Yes

Question	Question text	Change(s) made	Comparable to 2019
Q26	During the last 12 months, have you had an operation (such as removal of a tumour or lump) at one of the hospitals named in the covering letter?		Yes
Q27	Beforehand, did you have all the information you needed about your operation?		Yes
Q28	After the operation, did a member of staff explain how it had gone in a way you could understand?		Yes
Q29	During the last 12 months, have you stayed overnight for cancer care at one of the hospitals named in the covering letter?		Yes
Q30	Did hospital staff talk in front of you as if you weren't there?		Yes
Q31	Did you have confidence and trust in the doctors treating you?		Yes
Q32	If your family or someone else close to you wanted to talk to someone in the team looking after you during your stay in hospital, were they able to?	Question text changed. Response option added. Response options changed.	No
Q33	Did you have confidence and trust in the ward nurses treating you?		Yes
Q34	In your opinion, were there enough nurses on duty to care for you in hospital?		Yes
Q35	While you were in hospital did hospital staff ask you what name you prefer to be called by?		Yes
Q36	Were you given enough privacy when discussing your condition or treatment?		Yes

Question	Question text	Change(s) made	Comparable to 2019
Q37	During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?		Yes
Q38	Do you think the hospital staff did everything they could to help control your pain?		Yes
Q39	Overall, did you feel you were treated with respect and dignity while you were in the hospital?		Yes
Q40	Did you receive clear written information about what you should or should not do after leaving hospital?	Question text changed.	Yes
Q41	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?		Yes
Q42	During the last 12 months, have you been treated as an outpatient or day case for cancer care at one of the hospitals named in the covering letter?		Yes
Q43	While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?		Yes
Q44	The last time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?		Yes
Q45	During the last 12 months, have you had radiotherapy at any of the hospitals named in the covering letter?		Yes
Q46	Beforehand, did you have all of the information you needed about your radiotherapy treatment?		Yes

Question	Question text	Change(s) made	Comparable to 2019
Q47	Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?		Yes
Q48	During the last 12 months, have you had chemotherapy at any of the hospitals named in the covering letter?		Yes
Q49	Beforehand, did you have all of the information you needed about your chemotherapy treatment?		Yes
Q50	Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?		Yes
Q51	Did the team looking after you give your family or someone close to you all the information they needed to help care for you at home?	Question text changed. Response option removed. Response options changed.	No
Q52	During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?		Yes
Q53	Once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?		Yes
Q54	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?		Yes

Question	Question text	Change(s) made	Comparable to 2019
Q55	Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?		Yes
Q56	Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?		Yes
Q57	Have you been given a care plan?		Yes
Q58	Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc.)?		Yes
Q59	Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?		Yes
Q60	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?		Yes
Q61	Overall, how would you rate your care?		Yes