

Indigo survey

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Funded by:



Welcome to the Indigo cancer survey.

This national survey is for all people who have been diagnosed with cancer at any time in their adult life. Please tell us about the positive and negative aspects of your cancer diagnosis and treatment and how this may have affected your life. By sharing your experiences, you will be joining us in helping to improve the care, treatments and services people receive.

Before you decide to complete the survey, it is important for you to understand why the research is being done and what it will involve.

Please watch this animation below or you can read the patient information sheet by clicking [here](#). When you are happy to take part please click on the 'Take part' box on this page. You will then be able to complete the survey.

The survey works on all browsers, but it works best on Google Chrome or Firefox. If you have any problems, [please email us](#).

Thank you for reading this.

Link to the video: <https://youtu.be/cGr5uodTT2Q>

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So we can check that you are able to take part, were you over 16 years old when you were diagnosed with cancer?

☐ Yes

☐ No

Display This Question:

If So we can check that you are able to take part, were you over 16 years old when you were diagnose... = No

Thank you for answering this question.

From your answer it appears that you cannot take part in the study.

If you were under the age of 16 when you were diagnosed with cancer, then you cannot take part. Cancer treatment is very different in people under the age of 16 compared to over the age of 16 so the effects on people's lives are very different.

Did you finish your initial (first set) treatment(s) for cancer more than 12 months ago? (you can be on maintenance treatment, long term hormones or on further treatment and still take part)

☐ Yes

☐ No

Display This Question:

If Did you finish your initial (first set) treatment(s) for cancer more than 12 months ago? (you can... = No

Thank you for answering this question.

From your answer it appears that you cannot take part in the study.

If you are less than a year from receiving your diagnosis, then you are not eligible to take part in the study. The initial impact from the diagnosis and treatment need to settle. The impact of cancer and its treatment change over time. This is why we ask people to be more than 12 months from completing their initial treatment.

Where did you receive most of your cancer treatment?

- ☐ England
- ☐ Wales
- ☐ Scotland
- ☐ Northern Ireland
- ☐ Other (please, tell us below)

End of Block: Welcome

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Before starting the survey, what device are you on?

- ☐ Phone
- ☐ Tablet
- ☐ Computer

Do you want to complete the survey using this device? You will not be able to switch between devices once started.

- ☐ Yes
- ☐ No

Display This Question:

If Do you want to complete the survey using this device? You will not able to switch between devices... = No



Please tell us your email address we will send you a link to take part in the survey.

The email address you give us will not be joined up to your survey responses. Your responses will remain anonymous.

Your email address will be stored securely to allow us to send you the email. The email address will be deleted within 7 days. It will not be used for any other purpose than sending you a link to take part in the survey.

End of Block: Device

Start of Block: Consent

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I confirm that I have read the [participant information sheet](#) or watched the [animation](#) about this research study. I am aware of the email address (imperial.patients.indigo.trial@nhs.net) to contact the trial team, to ask questions and to ask for my data to be deleted.

☐ Yes

☐ No

Display This Question:

If I confirm that I have read the participant information sheet or watched the animation about this... =
No

To take part in this research you need to confirm that you understand what this survey study involves.

If you would like to take part, please watch the animation or [read the patient information sheet](#). If you have any questions, please email us (imperial.patients.indigo.trial@nhs.net). Then you can tick yes and take part.

I understand that my participation is voluntary, and I am free to withdraw at any time, without giving any reason and without my legal rights or treatment being affected.

☐ Yes

☐ No

Display This Question:

If I understand that my participation is voluntary, and I am free to withdraw at any time, without g... =
No

We are sorry. To take part in this research you need to give consent and answer yes to this question. If you would like to take part, please reconsider your answer to this question.

I agree to take part in the Indigo Study.

☐ Yes

☐ No

Display This Question:

If I agree to take part in the Indigo Study. = No

We are sorry. To take part in this research you need to give consent and answer yes to this question. If you would like to take part, please reconsider your answer to this question.

I understand that the research team will review information that I provide in the answers to the survey.

☐ Yes

☐ No

Display This Question:

If I understand that the research team will review information that I provide in the answers to the... =
No

We are sorry. To take part in this research you need to give consent and answer yes to this question. If you would like to take part, please reconsider your answer to this question.

I understand that data collected from me are a gift donated to Imperial College and that I will not personally benefit financially if this research leads to an invention and/or the successful development of a new test, medication treatment, product or service.

☐ Yes

☐ No

In the event of my incapacity or death my answers to this survey can be stored securely for research purposes for 10 years from the date the last participant takes part in the trial.

☐ Yes

☐ No

Display This Question:

*If In the event of my incapacity or death my answers to this survey can be stored securely for resea...
= No*

We are sorry. To take part in this research you need to give consent and answer yes to this question. If you would like to take part, please reconsider your answer to this question.

I agree for information collected about me to be used to support other research by an academic institution or commercial company in the future, including those outside of the United Kingdom (which Imperial has ensured will keep this information secure).

You can answer No to this question and still take part in this research study.

☐ Yes

☐ No

Display This Question:

If I understand that data collected from me are a gift donated to Imperial College and that I will n... =
No

We are sorry. To take part in this research you need to give consent and answer yes to this question. If you would like to take part, please reconsider your answer to this question.

I agree to being contacted about the possibility to take part in other research studies.

You can answer No to this question and still take part in this research study.

☐ Yes

☐ No

End of Block: Consent

Start of Block: Non-linkage

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Thank you for consenting to taking part in this research, the first questions will start after this page. Please press "Start" to begin.

End of Block: Non-linkage

Start of Block: Linkage

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The NHS stores information about your cancer journey. This information helps plan services and support research. NHS England and some regional databases keep this information.

This research will make more of a difference if we join your survey answers up with the NHS data on your cancer care.

The next question asks you if you agree to us to joining up your survey responses to the information the NHS holds about your cancer journey.

If you agree to us joining up your survey results with your NHS records, we will need some further personal details. This information would mean that it's possible for you to be identified if someone broke the law and shared that information.

You can read more details [on our website](#). If you choose not to agree to us linking your survey with your NHS records you can still take part in the rest of the survey. Your answers would still be very important to us and make a difference to future cancer patients' experiences.

Do you agree (consent) to the research team sending information you tell us in the survey to the NHS so that your answers can be joined up to information that the NHS holds about your cancer journey?

☐ Yes

☐ No

Display This Question:

*If Do you agree (consent) to the research team sending information you tell us in the survey to the...
= Yes*

Do you agree (consent) to NHS England sending us information about your NHS cancer journey so that we can use that information for research?

☐ Yes

☐ No

Display This Question:

If Do you agree (consent) to the research team sending information you tell us in the survey to the... = Yes

And Do you agree (consent) to NHS England sending us information about your NHS cancer journey so tha... = Yes

Thank you for agreeing to us joining your responses up with some of your NHS data.

To join your NHS records to the study, we need your first name, surname, date of birth, sex as recorded in your NHS records, and **full** postcode. Even if you've provided this information before, we need it again to ensure the NHS has your consent to link the survey to your records.

☐ First name _____

☐ Surname (family name) _____

☐ Date of birth (DD/MM/YYYY) _____

☐ Sex indicated in your NHS records _____

☐ Postcode (e.g., SW12 4XX) _____

Display This Question:

If Do you agree (consent) to the research team sending information you tell us in the survey to the... = No

Or Do you agree (consent) to NHS England sending us information about your NHS cancer journey so tha... = No

Thank you for answering that question.

We respect your answer, and we are not asking you to change your mind. It would be helpful for us to understand why you do not agree to linking your questionnaire responses to the cancer registry? (up to 500 characters)

End of Block: Linkage

Start of Block: Demographics 1

Timing

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Cancer and its treatments affect everyone differently. Some side effects impact people from certain backgrounds more. To help improve cancer care for everyone, we need to ask some personal questions.

You can miss out any question you don't want to answer but the more questions you can answer the more the research will be able to help everyone.



How old are you now (in years)?

Why are you asking this?

Age has an impact on our lives, whether we are affected by cancer or not. Knowing someone's age means we can interpret the results of your answers correctly.

What is your ethnicity?

Why are you asking this?

Ethnicity affects the types of cancer people get and some of the side effects of treatment. It can also affect the types of services people use to help reduce any problems they have after their cancer or its treatment.

- ☐ English, Welsh, Scottish, Northern Irish or British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White background
- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed or Multiple ethnic background
- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background
- ☐ African
- ☐ Caribbean
- ☐ Any other Black, African or Caribbean background
- ☐ Arab
- ☐ Any other ethnic group
- ☐ Prefer not to say

Display This Question:

If What is your ethnicity? = Any other ethnic group

Please, could you specify your ethnicity?

What is the post code where you live? Please provide the first half of your post code only. This means we can find out which part of the country you live in but we would not know exactly where you live. For example, if you live at SW15 4XX, please enter SW15.

What was your recorded sex at birth?

Why are you asking this?

People's sex at birth can have an impact on the effects that cancer and its treatment have on people.

- ☐ Male
- ☐ Female
- ☐ Intersex
- ☐ Prefer not to say
- ☐ If you want to give an answer that is not covered by one of these options, please tell us below: _____

Is the gender you now identify with the same as your sex recorded at birth?

Why are you asking this?

There is evidence that for people who identify with a different gender than recorded at birth have different experiences of cancer care and different impacts on their life. Knowing this information will help the research to improve care for everyone.

☐ Yes

☐ No

Display This Question:

If Is the gender you now identify with the same as your sex recorded at birth? = No

What gender do you identify with?

Why are you asking this?

We know that cancer and its treatment affect people differently. Some of these differences are caused by someone's gender and if they have changed gender.

☐ Male (including transman)

☐ Female (including transwoman)

☐ Non-binary

☐ I don't feel I have a gender identity

☐ If you want to give an answer that is not covered by one of these options, please tell us below: _____

☐ Prefer not to say

Which of these options best describes how you think of yourself?

Why are you asking this?

People's sexuality can impact how cancer and its treatment affect them.

- ☐ Straight / heterosexual
- ☐ Gay or lesbian
- ☐ Bisexual
- ☐ Queer
- ☐ Pansexual
- ☐ Asexual
- ☐ Unsure
- ☐ Prefer not to say

End of Block: Demographics 1

Start of Block: Cancer journey

Timing

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What type of cancer were you diagnosed with? If you have been diagnosed with more than one cancer tell us about the cancer you were most recently diagnosed with and then later we will ask about your other cancers.

This list is in alphabetical order. If you can't find the name of your cancer chose 'Other' and type your diagnosis.

- ☐ Acute lymphoblastic leukaemia (ALL)
- ☐ Acute Myeloid leukaemia (AML)
- ☐ Anal cancer
- ☐ Bile duct cancer (cholangiocarcinoma)
- ☐ Bladder cancer
- ☐ Blood cancers (if myeloma, leukaemia, lymphoma please tick those boxes)
- ☐ Bone cancer (bone sarcoma not secondary bone cancer)
- ☐ Bowel cancer
- ☐ Brain tumours
- ☐ Breast cancer
- ☐ Cancer of unknown primary (CUP)
- ☐ Cervical cancer
- ☐ Chronic lymphocytic leukaemia (CLL)
- ☐ Chronic myeloid leukaemia (CML)
- ☐ Colon cancer
- ☐ Craniopharyngioma
- ☐ Ductal carcinoma in Situ (DCIS)
- ☐ Endometrial (womb) cancer

- ☐ Eye cancer (ocular melanoma)
- ☐ Gallbladder cancer
- ☐ Gastro-intestinal Stromal Tumour (GIST)
- ☐ Head and neck cancer
- ☐ Hodgkin Lymphoma
- ☐ Kaposi's sarcoma
- ☐ Kidney cancer (renal cancer)
- ☐ Laryngeal (larynx) cancer
- ☐ Leukaemia (if ALL, AML, CLL or CML please tick those boxes)
- ☐ Lung cancer
- ☐ Lymphoma (not HL or NHL)
- ☐ Melanoma (skin cancer)
- ☐ Meningioma
- ☐ Mesothelioma
- ☐ Mouth cancer (lips, mouth, tongue)
- ☐ Myeloma
- ☐ Nasal and sinus cancer
- ☐ Nasopharyngeal cancer
- ☐ Neuroendocrine tumours (NETs)
- ☐ Non-Hodgkin Lymphoma (NHL)
- ☐ Oesophageal cancer

- ☐ Ovarian cancer
- ☐ Pancreatic cancer
- ☐ Parathyroid cancer
- ☐ Penis cancer
- ☐ Pineal region tumour
- ☐ Pituitary gland tumour
- ☐ Primary liver cancer
- ☐ Primary peritoneal cancer
- ☐ Prostate cancer
- ☐ Pseudomyxoma peritonei (PMP)
- ☐ Rectal cancer
- ☐ Salivary gland cancer
- ☐ Soft tissue sarcoma
- ☐ Small bowel cancer
- ☐ Spinal cord tumour
- ☐ Stomach cancer
- ☐ Testicular cancer
- ☐ Throat cancer (oropharynx, nasopharynx, hypopharynx)
- ☐ Thymus cancer
- ☐ Thyroid cancer
- ☐ Tongue cancer

- ☐ Trachea (windpipe) cancer
- ☐ Upper urinary tract urothelial cancer
- ☐ Vaginal cancer
- ☐ Vulval cancer
- ☐ Womb (endometrial cancer)
- ☐ Other (please specify)

Display This Question:

If What type of cancer were you diagnosed with? If you have been diagnosed with more than one cancer... = Other (please specify)

Please, could you specify the cancer you were diagnosed with?

What year were you diagnosed with your cancer*?

* Your most recent cancer if you have had more than one cancer.

▼ 2024 ... 1960

Thinking about **today**, how has your cancer* responded to treatment?

* Your most recent cancer if you have had more than one cancer.

- ☐ My cancer has responded to treatment (There are no signs of cancer at the moment)
 - ☐ My cancer has been treated but is still present
 - ☐ My cancer has not been treated at all
 - ☐ My cancer has come back after it was treated
 - ☐ I am not certain what is happening with my cancer
-

What treatment(s) did you receive? Please, tick all that apply for your cancer(s).

- ☐ Surgery (any operation for your cancer where the cancer or part of the cancer was removed)
 - ☐ Chemotherapy (any drugs which were given to try and kill or control the cancer)
 - ☐ Radiotherapy (radiation therapy to kill or control the cancer)
 - ☐ Brachytherapy (radioactive beads inserted into the body to deliver the radiotherapy to the area where the cancer was growing)
 - ☐ Immunotherapy (medication to help your immune system to fight the cancer)
 - ☐ Hormonal treatment (tablets, patches or implants to give hormones to reduce the chance of the cancer growing or returning)
 - ☐ Other (please, tell us below)
-

Approximately when was your last appointment at hospital with a doctor or specialist nurse who were part of the team that treated your cancer*?

* Your most recent cancer if you have had more than one cancer.

- ☐ Less than 12 months ago
- ☐ More than 12 months ago

You have told us about one cancer. Have you had any other types of cancer?

- ☐ Yes
- ☐ No

Display This Question:

If You have told us about one cancer. Have you had any other types of cancer? = Yes

How many other cancers have you been diagnosed with (not including your most recent cancer)?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5

Display This Question:

If How many other cancers have you been diagnosed with (not including your most recent cancer)? =

1

Please, could you tell us more about your other cancer diagnosis?

First diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)
-----------------	--

Display This Question:

If How many other cancers have you been diagnosed with (not including your most recent cancer)? =
2

Please, could you tell us more about your other cancer diagnoses?

First diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)
Second diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)

Display This Question:

If How many other cancers have you been diagnosed with (not including your most recent cancer)? =
3

Please, could you tell us more about your other cancer diagnoses?

First diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)
Second diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)
Third diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)

Display This Question:

If How many other cancers have you been diagnosed with (not including your most recent cancer)? =
4

Please, could you tell us more about your other cancer diagnoses?

First diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)
Second diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)
Third diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)
Fourth diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)

Display This Question:

If How many other cancers have you been diagnosed with (not including your most recent cancer)? =
5

Please, could you tell us more about your other cancer diagnoses?

First diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)
Second diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)
Third diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)
Fourth diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)
Fifth diagnosis	▼ Acute lymphoblastic leukaemia (ALL) ... Womb (endometrial cancer)

End of Block: Cancer journey

Timing

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Questionnaire 1



Health Questionnaire

English version for the UK

Please select the ONE box that best describes your health TODAY.

Mobility

- ☐ I have no problems in walking about
 - ☐ I have slight problems in walking about
 - ☐ I have moderate problems in walking about
 - ☐ I have severe problems in walking about
 - ☐ I am unable to walk about
-

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Please select the ONE box that best describes your health TODAY.

Self-care

- ☐ I have no problems washing or dressing myself
 - ☐ I have slight problems washing or dressing myself
 - ☐ I have moderate problems washing or dressing myself
 - ☐ I have severe problems washing or dressing myself
 - ☐ I am unable to wash or dress myself
-

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Please select the ONE box that best describes your health TODAY.

Usual activities (e.g. work, study, housework, family or leisure activities)

- ☐ I have no problems doing my usual activities
 - ☐ I have slight problems doing my usual activities
 - ☐ I have moderate problems doing my usual activities
 - ☐ I have severe problems doing my usual activities
 - ☐ I am unable to do my usual activities
-

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Please select the ONE box that best describes your health TODAY.

Pain / discomfort

- ☐ I have no pain or discomfort
 - ☐ I have slight pain or discomfort
 - ☐ I have moderate pain or discomfort
 - ☐ I have severe pain or discomfort
 - ☐ I have extreme pain or discomfort
-

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Please select the ONE box that best describes your health TODAY.

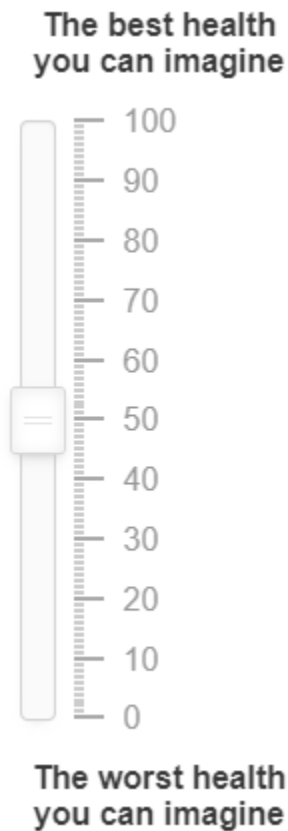
Anxiety / depression

- ☐ I am not anxious or depressed
 - ☐ I am slightly anxious or depressed
 - ☐ I am moderately anxious or depressed
 - ☐ I am severely anxious or depressed
 - ☐ I am extremely anxious or depressed
-

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We would like to know how good or bad your health is **today**.

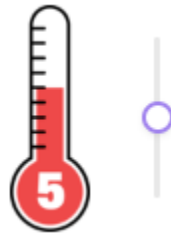
- You will see a scale numbered from 0 to 100.
- 100 means the best health you can imagine. 0 means the worst health you can imagine.



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Page Break

How would you rate your pain felt in the past week, including today (10 being the worst you can imagine)?



Do you think the questionnaire you have just completed (EQ-5D-5L) allowed you to share how you feel about your health and the impact cancer has on your life?



End of Block: EQ-5D-5L

Start of Block: Community services

Timing

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We would now like to know about any medical help you have had in the last year to help you manage any effects of your cancer or its treatment.

In the last 12 months have you seen any of the following people because of your cancer?

	At an NHS hospital	Not at an NHS hospital (e.g., at a GP practice, a clinic)
GP	<input type="checkbox"/>	<input type="checkbox"/>
Hospital doctor who is part of the team that treated me (consultant or one of their team)	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>
Occupational Therapist (OT)	<input type="checkbox"/>	<input type="checkbox"/>
Speech and language Therapist	<input type="checkbox"/>	<input type="checkbox"/>
Dietician	<input type="checkbox"/>	<input type="checkbox"/>
Stoma nurse	<input type="checkbox"/>	<input type="checkbox"/>
Palliative care team	<input type="checkbox"/>	<input type="checkbox"/>
Lymphoedema nurse / therapist	<input type="checkbox"/>	<input type="checkbox"/>
Clinical Psychologist	<input type="checkbox"/>	<input type="checkbox"/>
Counsellor	<input type="checkbox"/>	<input type="checkbox"/>
Cancer Care Co-ordinator	<input type="checkbox"/>	<input type="checkbox"/>

Care Navigator

☐☐

I have seen someone else

☐☐

Do you know who to contact if you have a concern about any aspect of living with or after cancer, for example if you were worried that your cancer had returned?

☐ Yes

☐ No

Display This Question:

If Do you know who to contact if you have a concern about any aspect of living with or after cancer,...
= Yes

Who would you be most likely to contact first?

☐ GP

☐ Specialist nurse / CNS / key worker at the hospital who treated me

☐ Doctor at the hospital

☐ Charity or support group

☐ Other (please, tell us below)

In the last 12 months have you taken any prescription medication (e.g., tablets, creams, implants) because of the effects of your cancer or its treatment? For example, to help with pain or other problems caused by the cancer or its treatment.

☐ Yes

☐ No

In the last 12 months have you used any non-medical help (e.g., supplements, holistic therapy) because of the effects of your cancer or its treatment? For example, to help with pain or other problems caused by the cancer or its treatment.

☐ Yes

☐ No

Thank you for answering the questions so far. The research will have more impact if we can repeat some of the questions in a year's time to see if there have been any changes.

Do you agree to continue to be involved in this research in the future? We would send you another survey by email in one year's time. It will be similar to the survey you have completed today.

☐ Yes

☐ No

Display This Question:

If Thank you for answering the questions so far. The research will have more impact if we can repeat... = Yes



Please, could you tell us the best email address to contact you? It won't be used for any other purpose, nor shared with third parties.

Start of Block: Demographics 2

Timing

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Thank you for answering the questions so far. We know that people's background affects the health services and care they receive. It will help us to understand the answers you have given us and to use the results to improve cancer care if we ask some more questions about you.

You can miss out any question you don't want to answer but the more questions you can answer the more the research will be able to help everyone.

Before your cancer diagnosis, which of the following **best** described your employment situation?

Why are you asking this?

Cancer and its treatment can affect people's ability to work, which has consequences for the rest of people's lives.

- ☐ Working (i.e., employed or self-employed)
 - ☐ Unemployed
 - ☐ Family carer
 - ☐ Full time student
 - ☐ Long term sick or disabled
 - ☐ Retired
-

Since you were diagnosed with cancer, which of the following **best** describes **any** change in your employment situation?

- ☐ Working (i.e., employed or self-employed)
- ☐ Unemployed
- ☐ Family carer
- ☐ Full time student
- ☐ Long term sick or disabled
- ☐ Retired
- ☐ No change because of cancer or its treatment

Display This Question:

If Since you were diagnosed with cancer, which of the following best describes any change in your em... = Working (i.e., employed or self-employed)

Since you were diagnosed with cancer, which of the following **best** describes **any** change in your employment situation?

- ☐ Employed, no changes (may have changed employer but no major change to the hours and type of work I do)
 - ☐ Employed, I have reduced my working hours
 - ☐ Employed, I have increased my working hours
 - ☐ Employed, I have changed my type of work because of my cancer or its treatment
 - ☐ I have been unable to work
-

What is your highest level of education, training or qualification?

Why are you asking this?

Education and training level can have an impact cancer has on someone. It can also make a difference to whether people take part in research.

- ☐ No Qualifications
 - ☐ Apprenticeship
 - ☐ GCSE's, School certification, BTEC first or general diploma, NVQ level 1 or 2, O levels, CSE
 - ☐ A-levels, Higher school certificate, NVQ level 3, GCE Advanced, International Baccalaureate, BTEC national
 - ☐ Degree or higher degree eg BA, BSc, MA, PhD, PGCE, NVQ level 4 or 5, HNC, HND, professional qualifications eg nursing, teaching, accountancy
 - ☐ Other vocational qualifications
 - ☐ Other (please, tell us below)
-

What is your current marital or civil partnership status?

Why are you asking this?

People's relationships can have an impact on how they manage health and social problems in their lives.

- ☐ Single (never been married or in a civil partnership)
- ☐ Single (previously married or in a civil partnership)
- ☐ Married or in a civil partnership
- ☐ In a relationship with someone and living with them
- ☐ In a relationship with someone but not living with them
- ☐ Widowed or surviving partner from a civil partnership
- ☐ Other (please, tell us below):

During your cancer journey have you taken part in any other research projects?

- ☐ Yes
- ☐ No
- ☐ I cannot remember

End of Block: Demographics 2

Timing

First Click

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Page Submit

Click Count

Thinking about your health in general, do you have any other health problems? Please tell us about any other medical problems you have. These may be problems that are not linked to your cancer and its treatment or they may have been caused by your treatment

Tick all the boxes that apply. We have given some examples to help you understand the question, but we are interested in any conditions which affect you.

☐ Heart and blood vessel problems – for example: high blood pressure, high cholesterol level, angina, heart attack, heart failure, heart rhythm problems, blocked arteries in the legs

☐ Lung and breathing problems – for example: asthma, COPD, emphysema, sleep apnoea

☐ Mental health problems – for example: anxiety, depression, bipolar, schizophrenia

☐ Bones and joint problems – for example: rheumatoid arthritis, osteoarthritis (wear and tear arthritis), reduced bone strength (osteoporosis), spinal problems

☐ Digestion and bowel problems – for example: reflux, gallstones, Crohn's disease, colitis, diverticulitis, liver disease

☐ Kidney and urine problems – for example: kidney disease, kidney failure, bladder problems, incontinence (leaking urine), recurrent urine infections

☐ Diabetes – type 1, type 2, treated with insulin or tablets

☐ Brain and nerve problems – for example: stroke, Parkinson's disease, multiple sclerosis, peripheral neuropathy

☐ Memory problems – for example mild cognitive impairment (MCI), any type of dementia

☐ Women's health problems – for example: reduced fertility, fertility treatment, early menopause, problems with heavy or irregular periods, endometriosis

☐ Men's health problems – for example: reduced fertility, erectile dysfunction, enlarged prostate gland

☐ Eye and ear problems – for example: hearing loss, vertigo, cataracts, macular degeneration, glaucoma

☐ Thyroid problems – under active or overactive thyroid gland

☐ Neurodiversity – for example: autism, ADHD, dyslexia

☐ Other (please, tell us below)

☐ I have no other health problems

Do you know your approximate height and weight?

☐ Yes

☐ No

Display This Question:

If Do you know your approximate height and weight? = Yes

Please, could you tell us your approximate height (in feet or in centimetres)?

☐ Feet (e.g. 5"11) _____

☐ Centimetres (e.g. 180) _____

Display This Question:

If Do you know your approximate height and weight? = Yes

Please, could you tell us your approximate weight (in stones or in kilograms)?

☐ Stones (e.g. 10) _____

☐ Kilograms (e.g. 65) _____

Do you think of yourself as having a disability?

☐ Yes

☐ No

Display This Question:

If Do you think of yourself as having a disability? = Yes

Which category of disability do you have? Please, tick all that apply.

☐

Problems with mental health

☐

Problems with vision (for example: blindness or partial sight)

☐

Problems with hearing (for example: deafness or partial hearing)

☐

Problems with speech

☐

Problems with arms or hands (for example: lifting or carrying things, using a keyboard)

☐

Problems with mobility (for example: walking short distances or climbing stairs)

☐

Problems with personal self-care (for example: cooking, cleaning, washing yourself)

☐

Problems with learning, understanding or concentrating

☐

Other (please, tell us below)

Have you made any changes to your lifestyle with the hope of reducing the chances of having any other problems with cancer in the future?

☐ Yes

☐ No

Display This Question:

If Have you made any changes to your lifestyle with the hope of reducing the chances of having any o... = Yes

Which aspects of your life have you tried to change? Please, tick all that apply.

- ☐ Stopped or reduced smoking (including vaping)
 - ☐ Lost weight / tried to maintain a healthy weight
 - ☐ Eat a healthy diet
 - ☐ Take regular exercise
 - ☐ Other (please, tell us below)
-

Display This Question:

If Which aspects of your life have you tried to change? Please, tick all that apply. = Lost weight / tried to maintain a healthy weight

Or Which aspects of your life have you tried to change? Please, tick all that apply. = Eat a healthy diet

Or Which aspects of your life have you tried to change? Please, tick all that apply. = Take regular exercise

Or Which aspects of your life have you tried to change? Please, tick all that apply. = Other (please, tell us below)

Or Which aspects of your life have you tried to change? Please, tick all that apply. = Stopped or reduced smoking (including vaping)

Do you feel that you were successful with changing your lifestyle?

☐ Yes

☐ No

End of Block: Your Health

Start of Block: Pre-randomisation

Timing

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If there is anything you would like to change in your previous answers, please do it now as you cannot go back after this page.

We want to understand which questionnaires are most helpful for people when describing their life after treatment for cancer. We want to compare different questionnaires. The questionnaires have all been developed by different research teams. They have been tested and have been shown to be helpful to some people. We want to compare them to see which patients find most useful.

We are going to show one of these questionnaires to you. A computer which does not have any information about you will decide which of the surveys you will see to make sure equal numbers of people use each one.

End of Block: Pre-randomisation

Start of Block: Social Difficulties Inventory

Timing

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Questionnaire 2: Social Difficulties Inventory

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These may be to do with things like their family life, social activities, finances, and work. We are interested in finding out what difficulties and problems patients have to cope with. Only when we find out the range and depth of these difficulties can we begin to make plans for giving support to patients who may need it.

INSTRUCTIONS

- Please read each question carefully and tick the response that best describes your answer.
- Please answer each question as honestly as possible
- If you are not completely sure which response is most accurate tick the box which you feel is the most appropriate.
- Please tick the "no difficulty" box if a question does not apply to you.
- Do not spend long on each statement.
 - There are 21 questions

ALL INFORMATION WILL BE TREATED CONFIDENTIALLY

During the past month

	No difficulty	A little	Quite a bit	Very much
Have you had any difficulty in maintaining your independence?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty with benefits? (e.g. statutory sick pay, attendance allowance, disability living)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

allowance)

Have you had
any financial
difficulties?

☐☐☐☐

During the past month

	No difficulty	A little	Quite a bit	Very much
Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty concerning your work? (or education if you are a student)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty with communicating with those closest to you? (e.g. partner, children, parents)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty concerning sexual matters?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Have you had
any difficulty
concerning plans
to have a family?

☐☐☐☐

During the past month

	No difficulty	A little	Quite a bit	Very much
Have you had any difficulty concerning your appearance or body image?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt isolated?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty with your plans to travel or take a holiday?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty with any other area of your everyday life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Do you think the questionnaire you have just completed (Social Difficulties Inventory) allowed to you share how you feel about your health and the impact cancer has on your life?



End of Block: Social Difficulties Inventory

Start of Block: EORTC QLQ-C30

Timing

First Click

Last Click

Page Submit

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Questionnaire 2: EORTC QLQ-C30

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers.

The information that you provide will remain strictly confidential.

	Not at all	A little	Quite a bit	Very much
Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have any trouble taking a long walk?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have any trouble taking a short walk outside of the house?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you need to stay in bed or a chair during the day?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you need help with eating, dressing, washing yourself or using the toilet?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the past week

	Not at all	A little	Quite a bit	Very much
Were you limited in doing either your work or other daily activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were you limited in pursuing your hobbies or other leisure time activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were you short of breath?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had pain?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you need to rest?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had trouble sleeping?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt weak?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the past week

	Not at all	A little	Quite a bit	Very much
Have you lacked appetite?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt nauseated?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you vomited?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been constipated?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had diarrhoea?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were you tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did pain interfere with your daily activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the past week

	Not at all	A little	Quite a bit	Very much
Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel tense?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you worry?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel irritable?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had difficulty remembering things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the past week

	Not at all	A little	Quite a bit	Very much
Has your physical condition or medical treatment interfered with your family life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Has your physical condition or medical treatment interfered with your social activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Has your physical condition or medical treatment caused you financial difficulties?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the past week

	Very poor	1	2	3	4	5	6	Excellent
How would you rate your overall health during the past week?	<input type="range"/>							
How would you rate your overall quality of life during the past week?	<input type="range"/>							

Do you think the questionnaire you have just completed (QLQ-C30) allowed you to share how you feel about your health and the impact cancer has on your life?



End of Block: EORTC QLQ-C30

Start of Block: Patient Generated Index

Timing

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Questionnaire 2: Patient Generated Index

Please tell us about **any** aspect, activity or thing in your life that have been most affected by the cancer or its treatment. You can give up to 5 answers but you can give less than this. It might be something general like your work or having a family or it could be a specific task such as being able to drive or put a jumper on. There are no right or wrong answers, the answers will be different for everyone. Some examples might include; money, marriage, self-esteem, energy, family life, sports, washing and dressing, walking. It can be anything large or small, but it is the parts of **your** life that have been affected by the cancer or its treatment. It does not matter what order you type the answers, the most important thing does not have to be put first.

☐ Enter the first area / thing of your life affected by cancer or its treatment

☐ Enter the second area / thing of your life affected by cancer or its treatment

☐ Enter the third area / thing of your life affected by cancer or its treatment

☐ Enter the fourth area / thing of your life affected by cancer or its treatment

☐ Enter the fifth area / thing of your life affected by cancer or its treatment

Carry Forward Entered Choices – Entered Text from "Please tell us about any aspect, activity or thing in your life that have been most affected by the cancer or its treatment. You can give up to 5 answers but you can give less than this. It might be something general like your work or having a family or it could be a specific task such as being able to drive or put a jumper on. There are no right or wrong answers, the

answers will be different for everyone. Some examples might include; money, marriage, self esteem, energy, family life, sports, washing and dressing, walking. It can be anything large or small, but it is the parts of your life that have been affected by the cancer or its treatment. It does not matter what order you type the answers, the most important thing does not have to be put first."



Now give each of the answers a score out of 10 for how much it has been affected by your cancer or its treatment. A score of 0 would mean that you are the worst you can imagine for yourself, and 10 would mean that you are not affected at all, and you are the best you can imagine.

You can keep moving the sliders until you feel the answer is right for you. You cannot break them; you can change them as much as you want until the answer seems right to you.

Worst you can imagine Not affected at all

0 1 2 3 4 5 6 7 8 9 10

Enter the first area / thing of your life affected by cancer or its treatment	
Enter the second area / thing of your life affected by cancer or its treatment	
Enter the third area / thing of your life affected by cancer or its treatment	
Enter the fourth area / thing of your life affected by cancer or its treatment	
Enter the fifth area / thing of your life affected by cancer or its treatment	

Carry Forward Entered Choices – Entered Text from "Please tell us about any aspect, activity or thing in your life that have been most affected by the cancer or its treatment. You can give up to 5 answers but you can give less than this. It might be something general like your work or having a family or it could be a specific task such as being able to drive or put a jumper on. There are no right or wrong answers, the answers will be different for everyone. Some examples might include; money, marriage, self esteem, energy, family life, sports, washing and dressing, walking. It can be anything large or small, but it is the parts of your life that have been affected by the cancer or its treatment. It does not matter what order you type the answers, the most important thing does not have to be put first."



Imagine you have 10 points to spend to show how important the parts of your life that have been affected by cancer or its treatment are to you. The more points you spend on an area the more important you are saying that area is to you.

You can spend all your points on one part of your life if you feel it is so important to you, but that means you won't have any points to spend on the other parts of your life. The sliders won't move if you have already 'spent' all your points unless you go back and reduce the points you've spent.

You can keep moving the sliders until you feel the answer is right for you. You can't break them, you can change them as much as you want. There are no right and wrong answers to this question

- _____ Enter the first area / thing of your life affected by cancer or its treatment
 - _____ Enter the second area / thing of your life affected by cancer or its treatment
 - _____ Enter the third area / thing of your life affected by cancer or its treatment
 - _____ Enter the fourth area / thing of your life affected by cancer or its treatment
 - _____ Enter the fifth area / thing of your life affected by cancer or its treatment
-

Do you think the questionnaire you have just completed (Patient Generated Index) allowed you to share how you feel about your health and the impact cancer has on your life?



End of Block: Patient Generated Index

Timing

First Click

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Click Count

Questionnaire 2: QLACS

In the past 4 weeks...

You had the energy to do the things you wanted to do.	▼ Never ... Always
You had difficulty doing activities that require concentrating.	▼ Never ... Always
You were bothered by having a short attention span.	▼ Never ... Always
You had trouble remembering things.	▼ Never ... Always
You felt fatigued.	▼ Never ... Always

In the past 4 weeks...

You felt happy.	▼ Never ... Always
You felt blue or depressed.	▼ Never ... Always
You enjoyed life.	▼ Never ... Always
You worried about little things.	▼ Never ... Always
You were bothered by being unable to function sexually.	▼ Never ... Always

In the past 4 weeks...

You didn't have energy to do the things you wanted to do.	▼ Never ... Always
You were dissatisfied with your sex life.	▼ Never ... Always
You were bothered by pain that kept you from doing the things you wanted to do.	▼ Never ... Always
You felt tired a lot.	▼ Never ... Always
You were reluctant to start new relationships.	▼ Never ... Always

In the past 4 weeks...

You lacked interest in sex.	▼ Never ... Always
Your mood was disrupted by pain or its treatment.	▼ Never ... Always
You avoided social gatherings.	▼ Never ... Always
You were bothered by mood swings.	▼ Never ... Always
You avoided your friends.	▼ Never ... Always

In the past 4 weeks...

You had aches or pains.	▼ Never ... Always
You had a positive outlook on life.	▼ Never ... Always
You were bothered by forgetting what you started to do.	▼ Never ... Always
You felt anxious.	▼ Never ... Always
You were reluctant to meet new people.	▼ Never ... Always

In the past 4 weeks...

You avoided sexual activity.	▼ Never ... Always
Pain or its treatment interfered with your social activities.	▼ Never ... Always
You were content with your life.	▼ Never ... Always

The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.

You appreciated life more because of having had cancer.	▼ Never ... Always
You had financial problems because of the cost of cancer surgery or treatment.	▼ Never ... Always
You worried that your family members were at risk of getting cancer.	▼ Never ... Always
You realized that having had cancer helps you cope better with problems now.	▼ Never ... Always
You were self-conscious about the way you look because of your cancer or its treatment.	▼ Never ... Always

The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.

You worried about whether your family members might have cancer-causing genes.	▼ Never ... Always
You felt unattractive because of your cancer or its treatment.	▼ Never ... Always
You worried about dying from cancer.	▼ Never ... Always
You had problems with insurance because of cancer.	▼ Never ... Always
You were bothered by hair loss from cancer treatment.	▼ Never ... Always

The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.

You worried about cancer coming back.	▼ Never ... Always
You felt that cancer helped you to recognize what is important in life.	▼ Never ... Always
You felt better able to deal with stress because of having had cancer.	▼ Never ... Always
You worried about whether your family members should have genetic tests for cancer.	▼ Never ... Always
You had money problems that arose because you had cancer.	▼ Never ... Always

The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.

You felt people treated you differently because of changes to your appearance due to your cancer or its treatment.

▼ Never ... Always

You had financial problems due to a loss of income as a result of cancer.

▼ Never ... Always

Whenever you felt a pain, you worried that it might be cancer again.

▼ Never ... Always

You were preoccupied with concerns about cancer.

▼ Never ... Always

Do you think the questionnaire you have just completed (QLACS) allowed you to share how you feel about your health and the impact cancer has on your life?



End of Block: QLACS_Phone

Start of Block: QLACS_Computer

Timing

First Click

Last Click

Page Submit

Click Count

Questionnaire 2: QLACS

In the past 4 weeks...

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
You had the energy to do the things you wanted to do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You had difficulty doing activities that require concentrating.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were bothered by having a short attention span.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You had trouble remembering things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You felt fatigued.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past 4 weeks...

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
You felt happy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You felt blue or depressed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You enjoyed life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You worried about little things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were bothered by being unable to function sexually.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past 4 weeks...

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
You didn't have energy to do the things you wanted to do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were dissatisfied with your sex life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were bothered by pain that kept you from doing the things you wanted to do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You felt tired a lot.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were reluctant to start new relationships.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past 4 weeks...

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
You lacked interest in sex.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your mood was disrupted by pain or its treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You avoided social gatherings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were bothered by mood swings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You avoided your friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past 4 weeks...

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
You had aches or pains.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You had a positive outlook on life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were bothered by forgetting what you started to do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You felt anxious.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were reluctant to meet new people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past 4 weeks...

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
You avoided sexual activity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain or its treatment interfered with your social activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were content with your life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
You appreciated life more because of having had cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You had financial problems because of the cost of cancer surgery or treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You worried that your family members were at risk of getting cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You realized that having had cancer helps you cope better with problems now.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were self-conscious about the way you look because of your cancer or its treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
You worried about whether your family members might have cancer-causing genes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You felt unattractive because of your cancer or its treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You worried about dying from cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You had problems with insurance because of cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were bothered by hair loss from cancer treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The next set of questions asks specifically about the effects of your cancer or its treatment.

Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
You worried about cancer coming back.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You felt that cancer helped you to recognize what is important in life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You felt better able to deal with stress because of having had cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You worried about whether your family members should have genetic tests for cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You had money problems that arose	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

because
you had
cancer.

The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
You felt people treated you differently because of changes to your appearance due to your cancer or its treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You had financial problems due to a loss of income as a result of cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whenever you felt a pain, you worried that it might be cancer again.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You were preoccupied with concerns about cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Do you think the questionnaire you have just completed (QLACS) allowed you to share how you feel about your health and the impact cancer has on your life?



End of Block: QLACS_Computer

Start of Block: Survey feedback

Timing

First Click

Last Click

Page Submit

Click Count

Are there symptoms or problems from your cancer or its treatment which you feel were not asked about in enough in detail in the two questionnaires you have just completed?

- ☐ Yes - There are problems related to my cancer or its treatment which the questions have not asked about fully
- ☐ No - I feel like the questions have covered all the parts of my life which could have been affected by my cancer or its treatment

Display This Question:

If Are there symptoms or problems from your cancer or its treatment which you feel were not asked ab... = Yes - There are problems related to my cancer or its treatment which the questions have not asked about fully

Which aspect of your life has been affected by your cancer or its treatment do you think the questions didn't cover in enough depth?

Tick all that apply.

- ☐ Pain
 - ☐ Mobility
 - ☐ Mental health
 - ☐ Sleep
 - ☐ Fatigue
 - ☐ Sexual health
 - ☐ Money & Finances
 - ☐ Employment
 - ☐ Other (please, tell us below)
-

Have you had any help to complete this survey?

- ☐ Yes
- ☐ No

Display This Question:

If Have you had any help to complete this survey? = Yes

What kind of help?

- ☐ Help to open the link or join the survey online
 - ☐ Help with using a computer, tablet, phone to take part
 - ☐ Help with getting data, broadband, access to the internet
 - ☐ Help with choosing the answers
 - ☐ Other (please, tell us below)
-

Do you have any suggestions for ways we can improve this survey?

End of Block: Survey feedback

Start of Block: Future contact

Timing

First Click

Last Click

Page Submit

Click Count

If you would like to find out what this research discovers and sharing your experience has contributed, please visit the [Computational Oncology website](#) for updates.

We would like to send you a short email in one (1) week's time with 2 quick questions (2 minutes to answer). We want to do this to check that you have been OK after the questionnaire and to see how you feel about it once you have had the chance to think about your experience. Do you agree to us sending you these questions?

☐ Yes

☐ No

Display This Question:

If We would like to send you a short email in one (1) week's time with 2 quick questions (2 minutes... = Yes



Please tell us the best email address to contact you. It won't be used for any other purpose, nor shared with third parties.

End of Block: Future contact
