

Indigo Community

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Tell us about your life after cancer

You can help make care after cancer better by taking part in the Indigo Community Project.

Please help us to discover what people need so that they can live the fullest life possible after cancer and its treatment. By completing this research questionnaire you can help to change the treatments and services patients receive in the future

If you want to part, please read the patient information sheet and Frequently Asked Questions below then click on the box below to agree to help us. You will then be able to either complete the questionnaire now or be emailed a link so that you can do it later when convenient for you.

There are answers to frequently asked questions below if you want to know more before taking part, just click on the question to read more.

Thank you.

Patient Information Sheet and Frequently Asked Questions

Why is the Indigo Community research project needed?

This research is needed so that better longer-term care and support can be provided for those of us treated for cancer. Very little is known about how cancer and its treatments affect the lives of patients, particularly in the long term.

Do I have to help?

It is up to you to decide whether or not to take part. This research will not make any changes to any treatment you are having. If you decide to take part on the next page you will be asked to give your consent (agreement) to take part in this study. If you agree to take part you are still free to withdraw at any time and without giving a reason and this won't affect your care or treatment.

How can you help?

We have created a questionnaire for patients to complete. This will improve the understanding of the lives of people who have had cancer including those who have or haven't received treatment. This will make it possible to organise services to provide the care and support that patients want; not what healthcare teams think they need.

Who can help?

Anyone who has been diagnosed and received (or did not want) any treatment for cancer who was over 16 years old when they were diagnosed. We want to hear from patients from any background, who have had any type of cancer and any type of treatment.

What do I have to do?

We invite you to help us and complete **this** questionnaire, which contains a series of questions. Some are tick boxes, others ask you to type a short answer. We hope you will answer all the questions but you will be able to miss questions out if you don't want to answer them for any reason.

This research questionnaire will take you approximately 30 minutes to complete. We realise this is a long time but you do not have to complete it all in one go. By taking part you will be helping us to design better questionnaires in the future making them more relevant, shorter and quicker to complete. Most importantly, we hope to make questionnaires that provide a better understanding of patients lives following a cancer diagnosis and treatment so that better care and support is provided.

You can complete this questionnaire on a smartphone, tablet or computer. Each answer provided is automatically saved so there is no need to save your answers. You can change your answers if you need to.

Can anyone help me complete the questionnaire?

Yes. You can have someone help you enter the answers or help you to remember what happened to you. Please remember that this questionnaire is about how you feel and what you can and cannot do, not what someone else thinks.

Are my answers confidential?

Yes, your answers are confidential. There are questions about this in the questionnaire so you are in charge of what happens and who sees your answers.

Will you know who I am? Will my answers be anonymous?

You are in charge of how much you tell us about yourself. You can take part in this research without us knowing who you are, and we will not be able to identify you. If we ask questions that would allow us to identify you we will tell you so you can decide if you want to answer or not.

Will it affect my care?

This research will not make any changes to any treatment you are having.

How will I benefit?

In the future we hope the results of this research will be used to improve the services patients receive. If you agree to being contacted to hear the results of the research there may be things you learn from others' experiences which help you live the fullest life possible after your treatment for cancer.

Are there any disadvantages to taking part?

It is very unlikely that taking part in this project will cause you any problems. In taking part in this project you will be giving us information. This information cannot be used to identify you. To make the data in this study as safe as possible we are using storage facilities that have the highest level of data security. However, there is still a very small risk that someone acting illegally could try to access this data but that should not cause you any problems as you would not be identifiable from that data.

There are extra questions in the study that ask you for information which can be used to identify you. You will be asked very clearly whether you agree to answer those questions or not. If you agree to share that information there is a bigger risk (but still very small) that if someone chose to act illegally and stole the data, then you could be identified.

Do I have to answer every question?

No. It helps more if you answer every question, but every answer help and also if you leave questions out then we learn what questions patients prefer not to answer.

Is everyone asked the same questions?

Most of the questions in the survey are the same for all people but there are two things that might be different.

You will be shown two questionnaires within the survey. All participants will be shown one questionnaire which is very commonly used in this type of research (called the EQ-5D-5L). There are 3 other questionnaires which we want to test to find out which patients think is most helpful. It would take a lot of time if everyone was asked to complete all 3 of these questionnaires. To save time for participants a better way test this is to only show people 1 of the 3 questionnaires. The fairest way to decide which questionnaire people are shown is to use something called "randomisation". A computer which does not have any information about you

will decide which of the 3 surveys you will see to make sure equal numbers of people use each one so we can test them fairly.

There is one other part of the survey which can be different so that not everyone completes the same survey. There is one question which will be shown to everyone but when you are shown the question will be different. It will be shown to half of participants near the start of the questionnaire and to the other half near the end of the questionnaire. We are doing this to see when people are shown this question affects how they answer it. Whether you see the question at near the start, or the end is decided by random using a computer which has no information about you. The only thing the computer does is to make sure that we have equal numbers of people seeing the question near the beginning or the end.

Do I have to complete the whole questionnaire in one go?

No. You can leave the questionnaire and return later using the same link and device (you can't start on one device and finish on a different one). You will be able to complete your answers for up to a week after you start it. If you don't return to finish the questionnaire, we will use the answers you have already given. However, your answers will make more of a difference to future patients if you can complete the whole questionnaire.

How accurate do my answers need to be?

The research asks you some questions about your cancer and its treatment. You do not need to be able to give us perfect answers. For example we ask a question about your date of diagnosis - give the answer as best as you can remember. Please do not feel that you have to go through letters or calendars to give us exact details. When we ask questions about how you feel and how your life is today these questions are best answered without thinking about it too much. Your gut instinct or your first thought is often the best answer.

What if the questionnaire makes me upset or triggers unhappy thoughts?

Usually, people who answer questions like these after being treated for cancer are not upset by the questions or by giving answers. However, some people may be affected. If that happens to you then talking to friends or family may be a good place to start. Or if you would prefer you can use the free Tenovus Cancer Care Support Line (0808 808 1010 or [use this link](#)), which is available 7 days a week to support you with questions or concerns about your cancer diagnosis, treatment or side-effects. Tenovus Cancer Care are not involved in this research so you can be open and honest with them. What you discuss with them is completely confidential. They will not tell us or your doctors what you say to them.

Tenovus Cancer Care will not be able to help you with completing the questionnaire or with any problems with digital devices or computers that you are using to complete the questionnaire.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should

immediately inform the Investigator (Dr M Williams, [send email](#)). The normal National Health Service complaints mechanisms are also available to you.

You can read more on our transparency notice: [link](#). The London Surrey Research Ethics Committee has reviewed and approved the study.

~~Are you on your preferred device to complete the questionnaire? It is easier on a tablet or computer but it is possible to do it on a phone. You can leave the questionnaire and return to the same device but you can't switch between two devices even if you stay on the same WiFi connection.~~

~~Yes~~

~~No~~

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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

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)

Yes

No

Were you diagnosed and/or treated in England? (You do not have to live in England at the moment)

Yes

No

End of Block: Welcome

Start of Block: Consent

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Consent

Consent (agreement) to take part in this research study

I confirm that I have read the Patient Information Sheet on the previous page about the Indigo community research study. I was given the opportunity to contact the trial team by email with any questions.

- Yes
 - No
-

I understand that taking part is voluntary and that I am free to withdraw at any time without giving any reasons and without my treatment or legal rights being affected.

- Yes
 - No
-

I understand that the research team will review information that I provide in the answers to the survey. I understand that they will not access my medical records or other data about me without my consent.

- Yes
 - No
-

I agree to my answers to this survey being stored securely for research purposes. I understand that storage will be for 10 years starting from today. In the event of my incapacity or death my answers to this survey can be stored securely for research purposes for 10 years starting from when new participants stop registering for this research project.

Yes

No

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

I consent (agree) to take part in the Indigo Community research project.

Yes

No

I agree that information collected about me in this research project can be used to support other research by an academic institution, the NHS or commercial company in the future.

Yes

No

I understand that I can contact the research team at any time and ask for my data to be deleted by sending an email to imperial.indigo.trial@nhs.net (or you can [click here](#).)

Yes

No

End of Block: Consent

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Information about you and your cancer journey is stored by the NHS. This information is used to plan cancer services and for research. Information is stored by NHS England and in some regional databases.

The impact of this research will be greater if we can join your survey answers up with the detailed information the NHS holds about your cancer care.

The next question asks you if you are happy for us to join up your survey responses to the information the NHS holds about your cancer journey.

Up until this point the information you have given us in this survey could not be used to identify you. If you agree to us joining up your survey results with your NHS records then you will give us information that means you could be identified if someone broke the law and shared that information.

There is more information below if you would like to know more. If you don't agree to us joining your survey answers to your NHS data that does not stop you from taking part in this research. We would still want to hear all about you and use your anonymous answers to improve future cancer patients' experiences and outcomes.

The NHS has information on the types of cancer and treatments you have had as well as where and when any treatments took place. But the databases do not have any information about any care or support you received outside hospital. Most importantly the NHS does not have detailed information about what you think about your current quality of life and what you can and cannot do after your cancer and its treatment.

For us to be able to join your survey up with the information the NHS has we would need two things:

1. Your agreement (consent) to do that.
2. You would need to tell us some information that means we can identify you. This would be your date of birth, full name (first name + surname) and full post code.

We would securely send that information to the national and local NHS groups so they could find your records in the database. They would then send us these records. This data would then be joined up to the questionnaire responses from this research.

All the data will be held securely at Imperial College London (who would be the data controller) and not shared with anyone else.

The data will be stored for 10 years as there will be a lot of research and investigation to do. Some results will be available very quickly but other might take several years of work. We need to keep the data long enough for things to be double checked and to be repeated.

NHS England and other local NHS groups will send us data from several databases:

- The National Cancer Registry. This contains information about your cancer and its treatment. For example, the stage and grade, treatments.
- The National Cancer Waiting Times Monitoring Data Set captures how long each step of your cancer pathway took from the time you were referred to hospital.
- The Hospital Episode Statistics records all hospital inpatient admissions, outpatient and A&E attendances for operations, clinic appointments and emergencies.
- The Diagnostic Imaging Dataset holds information about any scans you have had in the NHS.
- The Systemic Anti-Cancer Therapy dataset is about chemotherapy drugs which may have been used in your treatment (if you had chemotherapy as part of your treatment).
- The Radiotherapy Dataset holds records of your radiotherapy treatments (if you had radiotherapy as part of your treatment).
- The Cancer Pathway dataset represents each significant clinical or administrative event that the patient experiences as a single simple event record containing the “who, where, what, how, and when” of that event.
- The National Cancer Diagnosis Audit (NCDA) collected primary care data on the diagnostic pathway for patients diagnosed with cancer in 2014 and 2018.
- The National Cancer Patient Experience Survey (CPES) is a survey sent out to all adult cancer patients (aged 16 and over) with a primary diagnosis of cancer who have been admitted to an acute or specialist NHS Trust in England providing adult cancer services as inpatients or day cases, and discharged within a specified three month sampling period each year. The survey aims to collect information from patients about their cancer journey from their initial GP visit prior to diagnosis, through diagnosis and treatment and to the ongoing management of their cancer.
- The National Lung Cancer Audit (NLCA) looks at the care delivered during referral, diagnosis, treatment and outcomes for people diagnosed with lung cancer and mesothelioma.
- The Somatic Molecular Dataset records testing data directly from molecular diagnostics laboratories in England. A data set containing records of medicines dispensed in primary care settings, such as general practice, community clinics, dentists and nursing services.

- The Mental Health Services Data Set (MHSDS) collects data from the health records of individual children, young people and adults who are in contact with mental health services.
- The social care user surveys (ASCS and SACE data collections) ask people who are over 18 and who use adult social care about their experiences. The questionnaires look at how these services are helping people to live safely and independently in their own homes.

At the moment we cannot access data which is kept in your GP records. If that becomes possible in the future then we would join that data up with your questionnaires and other NHS data to give us a full picture of your entire cancer pathway from before you were referred and diagnosed to where you are today.

If you agree today but then change your mind you can withdraw your agreement to this at any time by sending an email to us imperial.indigo.trial@nhs.net and telling us that you would like to withdraw your consent and we will delete any data we hold about you. This will not affect your treatment or your legal rights.

Do you agree (consent) to the research team sending information you tell us to the NHS so that we can join (link) your questionnaire answers 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 to the NHS so that we... = Yes



Thank you for agreeing to us joining your responses up to cancer registries.

So that we can join it up we need you to tell us your first name, surname, your date of birth, your sex indicated in your NHS records and your full postcode.

- First name _____
 - Surname (family name) _____
 - Date of birth (dd/mm/yyyy) _____
 - Sex indicated in your NHS records _____
 - Postcode (e.g., SW12 4XX) _____
-

Do you agree (consent) to NHS England sending us information about your NHS cancer journey and us using that data for research?

- Yes
 - No
-

Display This Question:
If Do you agree (consent) to the research team sending information you tell us to the NHS so that we... = No



Thank you for answering that question.

We respect your answer and we are not asking you to change your mind. It would be really 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: Block for non-linkage

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

End of Block: Block for non-linkage

Start of Block: Demographics 1

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Some of these questions ask personal details. We are asking these questions so we can see if people from all walks of life take part.

The answers will not be shared with anyone else, and it would be very hard for anyone to identify you from this data. But we understand that you may not want to answer some of the questions. That is OK, you can leave the question blank and move on if that is what you would prefer to do.



How old are you now (in years)?

What is your ethnicity?

- 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

Demographics_C2_othe Please specify your ethnicity

What is the post code where you live? Please provide the first half of your post code (e.g. if you live at SW15 4XX, please enter "SW15")

How did you hear about this research project?

- I saw an advertisement myself ~~on-line~~online (social media, website)
- I saw a 'physical' advert myself (newspaper, poster)
- I was told about the study by friends or family
- I was told about the study by a healthcare professional e.g. GP, nurse, physiotherapist
- I received a message from the Primary Care Research Network telling me about the study
- I was told about the study by someone else e.g. religious leader, community group, charity

End of Block: Demographics 1

Start of Block: Cancer journey

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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)

- Breast
- Prostate
- Lung
- Colon
- Rectosigmoid junction
- Rectum
- Bowel (not sure what type)
- Melanoma
- Basal cell carcinoma
- Squamous cell carcinoma (SCC) of skin
- Skin (not sure what type)
- Non-Hodgkin Lymphoma
- Kidney
- Bladder
- Urinary (not sure what type)
- Lips, mouth, tongue
- Salivary glands (parotid gland, submandibular gland, sublingual gland)
- Tonsils
- Throat (oropharynx, nasopharynx, hypopharynx)
- Nasal cavity and middle ear
- Larynx

- Meninges
- Brain
- Spinal cord
- Cranial nerves
- Parathyroid gland
- Pituitary gland
- Craniopharyngeal duct
- Pineal gland
- Other
- Meninges
- Brain
- Spinal cord
- Cranial nerves
- Olfactory bulb
- Pituitary gland
- Craniopharyngeal duct
- Pineal gland
- Other
- Pancreas
- Acute lymphoblastic leukaemia (ALL)
- Chronic lymphocytic leukaemia (CLL)

- Acute myeloblastic leukaemia (AML)
- Chronic myeloid leukaemia (CML)
- Other leukaemia
- Leukaemia (not sure what type)
- Oesophagus
- Uterus
- Ovary
- Female genital organs (not sure what type)
- Cancer of Unknown Primary
- Stomach
- Liver
- Multiple myeloma and plasma cells
- Thyroid
- My cancer is not in this list

Display This Question:

If What type of cancer were you diagnosed with? (If you have been diagnosed with more than one cancer... = My cancer is not in this list

What type of cancer were you diagnosed with?

- Hodgkin Lymphoma
- Other lymphoma
- Other blood cancer
- Vulva
- Vagina
- Cervix
- Other female genital cancer
- Penis
- Testicles
- Other male genital cancer
- Ureter / urethra
- Bone or cartilage sarcoma
- Soft tissue sarcoma
- Kaposi sarcoma
- Adrenal
- Anus
- Eye
- Gallbladder
- Mesothelioma
- Parathyroid
- Small intestines (small bowel)

Trachea

Other

Display This Question:

If What type of cancer were you diagnosed with? = Other

Please, specify the cancer you were diagnosed with

Display This Question:

If What type of cancer were you diagnosed with? (If you have been diagnosed with more than one cancer... = Breast

Or What type of cancer were you diagnosed with? (If you have been diagnosed with more than one cancer... = Kidney

Or What type of cancer were you diagnosed with? (If you have been diagnosed with more than one cancer... = Meninges

Or What type of cancer were you diagnosed with? (If you have been diagnosed with more than one cancer... = Brain

Or What type of cancer were you diagnosed with? (If you have been diagnosed with more than one cancer... = Meninges

Or What type of cancer were you diagnosed with? (If you have been diagnosed with more than one cancer... = Brain

What side?

Left

Right

Both

Don't know

What year were you diagnosed with your cancer? (your most recent cancer if you have had more than one cancer)

- 2022
- 2021
- 2020
- 2019
- 2018
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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 did you receive? (for all cancers if you have had more than one cancer)
Tick all that apply.

- Surgery (any operation for your cancer where 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)
 - Any complimentary treatments not prescribed by the team looking after you (supplements, holistic therapies)
 - 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
-

Have you had more than one cancer?

- Yes
- No

Display This Question:
If Have you had more than one 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 Have you had more than one cancer? = Yes
And How many other cancers have you been diagnosed with (not including your most recent cancer)? = 1

Please, tell us more about your other cancer diagnosis

	What type of cancer was it?
First diagnosis	▼ Breast ... My cancer is not in this list

Display This Question:
If Have you had more than one cancer? = Yes
And How many other cancers have you been diagnosed with (not including your most recent cancer)? = 2

Please, tell us more about your other cancer diagnoses

	What type of cancer was it?
--	-----------------------------

First diagnosis
Second diagnosis

▼ Breast ... My cancer is not in this list
▼ Breast ... My cancer is not in this list

Display This Question:

If Have you had more than one cancer? = Yes

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

Please, tell us more about your other cancer diagnoses

What type of cancer was it?

First diagnosis
Second diagnosis
Third diagnosis

▼ Breast ... My cancer is not in this list
▼ Breast ... My cancer is not in this list
▼ Breast ... My cancer is not in this list

Display This Question:

If Have you had more than one cancer? = Yes

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

Please, tell us more about your other cancer diagnoses

What type of cancer was it?

First diagnosis
Second diagnosis
Third diagnosis
Fourth diagnosis

▼ Breast ... My cancer is not in this list
▼ Breast ... My cancer is not in this list
▼ Breast ... My cancer is not in this list
▼ Breast ... My cancer is not in this list

Display This Question:

If Have you had more than one cancer? = Yes

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

Please, tell us more about your other cancer diagnoses

	What type of cancer was it?
First diagnosis	▼ Breast ... My cancer is not in this list
Second diagnosis	▼ Breast ... My cancer is not in this list
Third diagnosis	▼ Breast ... My cancer is not in this list
Fourth diagnosis	▼ Breast ... My cancer is not in this list
Fifth diagnosis	▼ Breast ... My cancer is not in this list

End of Block: Cancer journey

Start of Block: EQ-5D-5L

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Questionnaire 1 (EQ-5D-5L)

Under each heading, please tick **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
-

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

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
-

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
-

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

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



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



Do you think a doctor or nurse who read the answers from the EQ-5D-5L questionnaire ("Questionnaire 1") would have a good understanding of what you can and can't do?

0 being "this questionnaire did not help me to describe my life" and 10, "this questionnaire perfectly captured my quality of life".



End of Block: EQ-5D-5L

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Because of your cancer or its treatment, have you seen any of these health or care professionals in the community (not at the hospital) in the last 12 months?

- GP
 - Physiotherapists
 - Occupational therapists
 - Speech and language therapists
 - Clinical Psychologists
 - Dieticians
 - Stoma Nurses
 - Palliative care team
 - Other (please, tell us below)
-

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 medication regularly (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 (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

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?

- 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)
-

End of Block: Community services

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Thinking about your health in general, do you have any other health problems?

Please tell us which parts of your health you have problems with. 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 disease – for example angina, heart attack, heart failure, heart rhythm problems, blocked arteries in the legs
- Lung disease – for example asthma, COPD, Emphysema
- Abdominal disease – for example Crohn's disease, Colitis, liver disease, kidney disease
- Diabetes – including problems caused by diabetes for example eye, kidney and nerve problems
- Neurological – for example stroke, Parkinson's disease, Multiple sclerosis, dementia
- Mental Health – for example anxiety, depression, bipolar, schizophrenia
- Bones and joints – for example rheumatoid arthritis, osteoarthritis (wear and tear arthritis)
- Women's health - for example fertility treatment, early menopause, problems with heavy or irregular periods
- Other (Please tell us)

- 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 tell us your approximate height (in feet or in centimetres)

Feet (e.g. 5"11) _____

Centimetres (e.g. 180 cm)

Display This Question:
If Do you know your approximate height and weight ? = Yes

Please tell us your approximate weight (in stones or in kilograms)

Stones (e.g. 10~~st~~) _____

Kilograms (e.g. 65~~kg~~) _____

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?

- Problems with mental health (e.g., depression)
 - Problems with sight
 - Problems with hearing
 - Problems with speech
 - Problems with physical health (arms)
 - Problems with physical health (legs)
 - Problems with personal, self-care, continence
 - Problems with learning disabilities
 - Other (please, tell us below)
-

End of Block: Your Health

Start of Block:

Timing

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We want to understand which questionnaires are most helpful for patients when describing their life after treatment for cancer. We want to compare 3 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 would like your help to answer this question.

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.

Please, before you go further, if there is anything you would like to in your previous answers as you cannot go back after this page.

End of Block:

Start of Block: Social Difficulties Inventory

Timing
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Questionnaire 2

During the past month

	No difficulty	A little	Quite a bit	Very much
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 difficulty with the support available to them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Have you had any financial difficulties?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had 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 difficulty concerning your work? (or education if you are a student)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the past month

	No difficulty	A little	Quite a bit	Very much
Have you had difficulty planning for your own or your families 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,	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

neighbours, colleagues, dates)				
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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you had any difficulty concerning your appearance or body image?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the past month

	No difficulty	A little	Quite a bit	Very much
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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

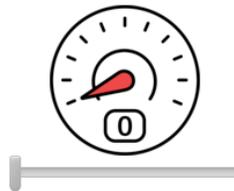
hobbies, past times, social pursuits)

Have you had any difficulty with your plans to travel or take a holiday?

Have you had any difficulty with any other areas of your everyday life?

Do you think a doctor or nurse who looked the answers from the SDI questionnaire ("Questionnaire 2") would have a good understanding of what you can and can't do?

0 being "this questionnaire did not help me to describe my life" and 10, "this questionnaire perfectly captured my quality of life".



End of Block: Social Difficulties Inventory

Start of Block: EORTC QLQ-C30

Timing
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Questionnaire 2

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 diarrhea?	<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	7	Excellent
How would you rate your overall health during the past week?									
How would you rate your overall quality of life during the past week?									

Do you think a doctor or nurse who looked the answers from the QLQ-C30 questionnaire ("Questionnaire 2") would have a good understanding of what you can and can't do?

0 being "this questionnaire did not help me to describe my life" and 10, "this questionnaire perfectly captured my quality of life".



End of Block: EORTC QLQ-C30

Start of Block: Patient Generated Index

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Questionnaire 2

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 / ingredient of your life affected by cancer or its treatment

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

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

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

Enter the fifth area / thing / ingredient 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	0	1	2	3	4	5	6	7	8	9	10	Not affected at all
<p>Enter the first area / thing / ingredient of your life affected by cancer or its treatment</p>													
<p>Enter the second area / thing / ingredient of your life affected by cancer or its treatment</p>													
<p>Enter the third area / thing / ingredient of your life affected by cancer or its treatment</p>													
<p>Enter the fourth area / thing / ingredient of your life affected by cancer or its treatment</p>													
<p>Enter the fifth area / thing / ingredient of your life affected by cancer or its treatment</p>													

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.

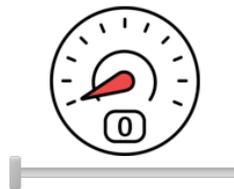
You can spend all your points on one part of your life if you feel it is so important to you, but that means you won't have any points to spend on the other parts of your life. The sliders won't move if you have already 'spent' all your points unless you go back and reduce the points you've spent.

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.

	0	1	2	3	4	6	7	8	9	10
Enter the first area / thing / ingredient of your life affected by cancer or its treatment										
Enter the second area / thing / ingredient of your life affected by cancer or its treatment										
Enter the third area / thing / ingredient of your life affected by cancer or its treatment										
Enter the fourth area / thing / ingredient of your life affected by cancer or its treatment										
Enter the fifth area / thing / ingredient of your life affected by cancer or its treatment										

Do you think a doctor or nurse who looked the answers from the PGI questionnaire ("Questionnaire 2") would have a good understanding of what you can and can't do?

0 being "this questionnaire did not help me to describe my life" and 10, "this questionnaire perfectly captured my quality of life".



End of Block: Patient Generated Index

Start of Block: Patient Generated Index - no validation

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Questionnaire 2

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 / ingredient of your life affected by cancer or its treatment

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

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

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

- Enter the fifth area / thing / ingredient 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.

	0	1	2	3	4	5	6	7	8	9	10
Enter the first area / thing / ingredient of your life affected by cancer or its treatment											
Enter the second area / thing / ingredient of your life affected by cancer or its treatment											
Enter the third area / thing / ingredient of your life affected by cancer or its treatment											
Enter the fourth area / thing / ingredient of your life affected by cancer or its treatment											
Enter the fifth area / thing / ingredient 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.

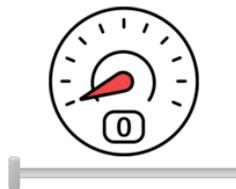
You can spend all your points on one part of your life if you feel it is so important to you, but that means you won't have any points to spend on the other parts of your life. The sliders won't move if you have already 'spent' all your points unless you go back and reduce the points you've spent.

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.

	0	1	2	3	4	6	7	8	9	10
Enter the first area / thing / ingredient of your life affected by cancer or its treatment										
Enter the second area / thing / ingredient of your life affected by cancer or its treatment										
Enter the third area / thing / ingredient of your life affected by cancer or its treatment										
Enter the fourth area / thing / ingredient of your life affected by cancer or its treatment										
Enter the fifth area / thing / ingredient of your life affected by cancer or its treatment										

Do you think a doctor or nurse who looked the answers from the PGI questionnaire ("Questionnaire 2") would have a good understanding of what you can and can't do?

0 being "this questionnaire did not help me to describe my life" and 10, "this questionnaire perfectly captured my quality of life".



End of Block: Patient Generated Index - no validation

Start of Block: Survey feedback

Timing

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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 it's treatment which you feel were not asked a... = 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 take part in this research? / Did you need any help to complete this questionnaire?

- Yes
- No

Display This Question:

If Have you had any help to take part in this research? / Did you need any help to complete this que... = 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)
-

Display This Question:

If Have you had any help to take part in this research? / Did you need any help to complete this que... = Yes

Who helped you?

- Family member
 - Friend or neighbour
 - Member of community or faith group
 - Charity
 - Other (please, tell us below)
-

End of Block: Survey feedback

Start of Block: Demographics 2

Timing

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Click Count

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

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

Display This Question:

If Since you were diagnosed with cancer which of the following BEST describes ANY change in your emp... = 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
-

So that we can make sure that we have heard from people from all parts of society we would like to ask some more questions about you. These are quite personal, but your answers will be treated confidentially and they will help us to improve cancer care for EVERYONE.

What was your recorded sex at birth?

- 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 you answer below _____
-

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

- Yes
- No
- Prefer not to say

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?

- Male (including transman)
- Female (including transwoman)
- Non-binary
- Prefer not to say
- 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 you answer below _____

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

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

What is your highest level of training or qualification?

- Higher degree (e.g. MA, MSC, PhD)
 - First degree
 - A-levels or equivalent (e.g., GCE Advanced, International Baccalaureate)
 - GCSE's or equivalent (e.g., CSEs)
 - Commercial qualifications no GCSE's
 - Apprenticeship
 - Other (please, tell us below)
-

- None
-

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

- Yes
- No
- I cannot remember

End of Block: Demographics 2

Start of Block: Future contact

Timing
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Future contact

	Yes	No
<p>Would you like to receive an email update telling you what has been learnt from this research and how this information will improve the care of patients with cancer?</p>	<input type="radio"/>	<input type="radio"/>
<p>We would like to send you a short email in 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?</p>	<input type="radio"/>	<input type="radio"/>
<p>Do you agree to continuing to be involved in this research in the future? We would send you another questionnaire by email in one year’s time. It would be the same or very similar to the questionnaire you have completed today.</p>	<input type="radio"/>	<input type="radio"/>
<p>Do you agree to the research team using the information collected about you in this research for other research in the future. That might include it being shared anonymously (with your personal details</p>	<input type="radio"/>	<input type="radio"/>

removed) with other
researchers.

Display This Question:

If Future contact = Would you like to receive an email update telling you what has been learnt from this research and how this information will improve the care of patients with cancer? [Yes]

Or Future contact = We would like to send you a short email in 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]



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
