

QUESTIONNAIRE



National
Cancer Care
Experience
Survey

What is the survey about?

The National Cancer Care Experience Survey is the first national survey to ask adults about their experience of cancer care in Ireland. The results of the survey will be used to improve and shape cancer services.

Please use this questionnaire to provide general feedback about your hospital experience. If you would like to make a comment or complaint and receive a response, please email the HSE at yoursay@hse.ie or phone 1800 424 555. You can also contact the Patient Advocacy Service, an independent advocacy service, which supports people who wish to make a complaint, at 0818 293 003 or info@patientadvocacyservice.ie

Why did I get this questionnaire?

You have received this questionnaire because you are aged 16 years or over and received cancer care as an inpatient or day case in hospital between October and December 2026.

Can I ask someone to help me fill in the questionnaire?

Yes, you can ask someone to help you fill in this questionnaire. You may also ask someone to fill in the questionnaire on your behalf. However, the answers given should still reflect your experience of care.

Completing the questionnaire

- If you have had more than one cancer diagnosis, please think about your most recent diagnosis when completing this questionnaire.
- When answering the questions, please think of your most recent experience of cancer care as an inpatient or day case at the hospital named in the letter you received with this questionnaire.
- There may be some questions that are not relevant to you. Please read the information in the boxes that accompany some of the questions as these provide important information to help you complete the questionnaire. Please answer all the questions that are relevant to your experience.
- The questionnaire takes about 30 minutes to complete.
- For each question, please tick ☒ the appropriate box (or boxes) using a black or blue pen. Do not worry if you make a mistake; simply fill in the box ☐ and put a tick ☒ in the correct box.
- There is space at the end of the questionnaire for your written comments.
- Please do not write your name or address anywhere on the questionnaire.
- Please return this questionnaire in the Freepost envelope provided. No stamp is needed.
- You can also complete the survey online using the text message sent to you from CareSurvey. The text message contains a link that directs you to the survey.

If you have any questions about the survey, please call our Freephone number on 1800 314 093 (Monday-Friday, 9am-5pm) or email us at info@yourexperience.ie.

If you do not want to take part in the survey and would prefer not to hear from us again, please call the Freephone number on 1800 314 093 or email us at info@yourexperience.ie

Please be assured that your answers will remain confidential and your feedback will not affect your current or future care in anyway.

Survey Code:

Improving care experiences together



An Roinn Sláinte
Department of Health



Section 1: Before you knew you had cancer

The questions in this section ask about what happened before you knew you had cancer.

Q1. How was your cancer first detected?

- ☐ I attended my General Practitioner (GP) for my symptoms and I was then referred to a hospital → **Go to Q2**
- ☐ I attended routine cancer screening (for example BreastCheck, Cervical Check or BowelScreen) → **Go to Q4**
- ☐ I attended the emergency department for my symptoms → **Go to Q4**
- ☐ Annual health screening → **Go to Q4**
- ☐ Other → **Go to Q4**
- ☐ Don't know or can't remember → **Go to Q4**

Q2. If you were referred for diagnostic tests by your GP, did staff at your GP practice explain why you were being referred in a way you could understand?

- ☐ Yes, completely
- ☐ Yes, to some extent
- ☐ No
- ☐ I wasn't referred by my GP practice
- ☐ Don't know or can't remember

Q3. Overall, how did you feel about the length of time between when your diagnostic test was ordered and when it was completed?

- ☐ It was about right
- ☐ It was a little too long
- ☐ It was much too long
- ☐ Don't know or can't remember

Section 2: Diagnostic tests

The questions in this section ask about your experience of any tests you may have had to help diagnose your cancer. This could have been a blood test, scan, biopsy or endoscopy, for example. When answering these questions, please think about the last the time you had a diagnostic test or tests for your cancer.

Q4. In the last 12 months, have you had any tests that helped to diagnose your cancer at the hospital named in the cover letter you received with this questionnaire?

- ☐ Yes → **Go to Q5**
- ☐ No → **Go to Q6**

Q5. Were the results of the tests explained in a way you could understand?

- ☐ Yes, completely
- ☐ Yes, to some extent
- ☐ No
- ☐ I didn't have an explanation but would have liked one
- ☐ I haven't received the results yet
- ☐ Don't know or can't remember

Section 3: Finding out about your cancer

The questions in this section ask about your interactions and experiences when you found out you had cancer.

Q6. When you were first told you had cancer, were you given the option of having a family member, carer or friend with you while being told?

- ☐ Yes, I was told I could have someone with me
- ☐ No, I was not given the option to have someone with me
- ☐ No, I was specifically told I could not have someone with me
- ☐ No, I was told by letter, phone or email
- ☐ Don't know or can't remember

Q7. Was your diagnosis explained to you in a way you could understand?

- ☐ Yes, completely
- ☐ Yes, to some extent
- ☐ No
- ☐ Don't know or can't remember

Q8. Were you told about your cancer diagnosis in a sensitive way?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ Don't know or can't remember

Q9. When you were told you had cancer, were you given written information about the cancer type?

- ☐ Yes, and it was easy to understand
- ☐ Yes, but it was difficult to understand
- ☐ No, I didn't get any written information
- ☐ I did not need nor want written information
- ☐ Don't know or can't remember

Section 4: Support from a main contact person

The questions in this section ask about support you may have received from a main contact person within the team of staff looking after you, throughout your cancer care and treatment.

Q10. Did you have a main contact person within the team of staff looking after you, such as a clinical nurse specialist, who would support you through your treatment?

- ☐ Yes → Go to Q11
- ☐ No → Go to Q12
- ☐ Don't know or can't remember → Go to Q12

Q11. How easy has it been to contact your main contact person?

- ☐ Very easy
- ☐ Quite easy
- ☐ Neither easy nor difficult
- ☐ Quite difficult
- ☐ Very difficult
- ☐ I haven't needed to contact this person

Section 5: Deciding on the best treatment for you

The questions in this section ask about your experience of deciding on the best treatment options for you. This section also looks at how you were supported with any worries or needs you may have had.

Q12. Before your cancer treatment started, were your treatment options explained to you in a way you could understand?

- ☐ Yes, completely
- ☐ Yes, to some extent
- ☐ No
- ☐ There was only one type of treatment option available to me
- ☐ Don't know or can't remember

Q13. Were you involved as much as you wanted to be in decisions about your treatment options?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ Don't know or can't remember

Q14. Before your treatment started, did you have a discussion with a hospital staff member about your needs or concerns?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No, and I wanted this
- ☐ No, but I didn't want this
- ☐ Don't know or can't remember

Q15. Did you feel you had enough time to discuss your care and treatment with a doctor?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No

Section 6: Hospital care

The questions in this section ask you about your experience of care during any overnight hospital stays.

Q16. During the last 12 months, have you stayed overnight for cancer care at the hospital named in the letter you received with this questionnaire?

- ☐ Yes → Go to Q17
- ☐ No → Go to Q21

Thinking about the last time you stayed overnight in hospital...

Q17. Could you get help from staff on the ward when you needed it?

- ☐ Yes, always
- ☐ Yes, sometimes
- ☐ No
- ☐ I didn't need any help
- ☐ Don't know or can't remember

Q18. Could you talk with hospital staff about your worries or fears?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ I had no worries or fears
- ☐ Don't know or can't remember

Q19. Did the hospital staff do everything they could to help manage your pain?

- ☐ Yes, always
- ☐ Yes, sometimes
- ☐ No
- ☐ I was never in any pain
- ☐ Don't know or can't remember

Q20. Did hospital staff give you information about what you should or should not do after leaving the hospital?

- ☐ Yes
- ☐ No
- ☐ I didn't want or need any information
- ☐ Don't know or can't remember

Section 7: Your treatment

The questions in this section ask you about the types of care and treatment(s) you received for your cancer.

Q21. During the last 12 months, have you had any of the following? Tick all that apply.

- ¹ ☐ Surgery → **Go to Q22**
- ² ☐ Chemotherapy (including immunotherapy) → **Go to Q22**
- ³ ☐ Radiation therapy → **Go to Q22**
- ⁴ ☐ Hormone therapy → **Go to Q22**
- ⁵ ☐ Palliative care → **Go to Q24**
- ⁶ ☐ None of these → **Go to Q24**

Q22. Before your treatment started, were you given all the information you needed about the treatment in a way that you could understand? Please answer for each treatment you ticked in Q21.

	Yes, completely	Yes, to some extent	No	Don't know or can't remember
Surgery	¹ ☐	² ☐	³ ☐	⁴ ☐
Chemotherapy (including immunotherapy)	¹ ☐	² ☐	³ ☐	⁴ ☐
Radiation therapy	¹ ☐	² ☐	³ ☐	⁴ ☐
Hormone therapy	¹ ☐	² ☐	³ ☐	⁴ ☐

Q23. On average, how long did you have to wait for your treatment to start when you arrived at the hospital? Please answer for each appropriate treatment you ticked in Q21.

	I usually waited less than 30 minutes	I usually waited between 30 minutes to 1 hour	I usually waited between 1 to 2 hours	I usually waited over 2 hours
Chemotherapy (including immunotherapy)	¹ ☐	² ☐	³ ☐	⁴ ☐
Radiation therapy	¹ ☐	² ☐	³ ☐	⁴ ☐

Section 8: Care and support from hospital staff

The questions in this section ask about your interactions and experiences with hospital staff throughout your cancer treatment.

Q24. Which of the following people did you meet in hospital during your cancer care and treatment? Tick all that apply.

- ☐ 1 Consultant Haematologist
- ☐ 2 Consultant Medical Oncologist
- ☐ 3 Consultant Radiation Oncologist
- ☐ 4 Consultant Surgeon
- ☐ 5 Dentist
- ☐ 6 Dietitian
- ☐ 7 Nursing Staff
- ☐ 8 Occupational Therapist
- ☐ 9 Pharmacist
- ☐ 10 Physiotherapist
- ☐ 11 Psychiatrist
- ☐ 12 Psychologist
- ☐ 13 Radiation Therapist
- ☐ 14 Social Worker
- ☐ 15 Speech and Language Therapist
- ☐ 16 Other medical staff

Q25. Were you able to get advice or access support from a hospital staff member for your nutritional needs?

- ☐ 1 Yes
- ☐ 2 No, and I wanted advice or support
- ☐ 3 I didn't need advice or support
- ☐ 4 Don't know or can't remember

Q26. Did you receive enough emotional and psychological support from your team of hospital staff during your cancer treatment?

- ☐ 1 Yes, definitely
- ☐ 2 Yes, to some extent
- ☐ 3 No
- ☐ 4 I didn't need emotional or psychological support
- ☐ 5 Don't know or can't remember

Q27. Did the hospital staff looking after you give your family or someone close to you, the information they needed to care for you at home?

- ☐ 1 Yes, definitely
- ☐ 2 Yes, to some extent
- ☐ 3 No
- ☐ 4 Not applicable to my situation
- ☐ 5 Don't know or can't remember

Q28. Did the hospital staff give you information that was relevant to you about local community cancer support, events or resources for people with cancer?

- ☐ 1 Yes
- ☐ 2 No, and I would have liked this information
- ☐ 3 No, but I didn't want or need this information
- ☐ 4 Don't know or can't remember

Q29. If you have had cancer treatment (like chemotherapy, radiotherapy), you may have been given information about how to contact the SOS (Sort Out my Symptoms) hotline if you felt unwell. If you did feel unwell, did you use the SOS hotline?

- ☐ 1 Yes, I used it
- ☐ 2 No, I didn't need to use it
- ☐ 3 No, I wasn't aware of this service
- ☐ 4 I wanted to use it, but it wasn't available
- ☐ 5 I was given a different contact number or service
- ☐ 6 Not applicable to my situation
- ☐ 7 Don't know or can't remember

Section 9: Emergency Department attendance

The questions in the following section ask you about your experience of any emergency care that required emergency department attendance during your cancer treatment.

Q30. Have you ever gone to the emergency department because you felt unwell due to your cancer or cancer treatment?

- ☐ ¹ Yes, once → **Go to Q31**
- ☐ ² Yes, more than once → **Go to Q31**
- ☐ ³ No, never → **Go to Q32**
- ☐ ⁴ Don't know or can't remember → **Go to Q32**

Q31. Thinking about your last trip to the emergency department, if you were told you were being admitted, how long did it take for you to receive a bed on a ward?

- ☐ ¹ Less than 6 hours
- ☐ ² Between 6 and up to 12 hours
- ☐ ³ Between 12 and up to 24 hours
- ☐ ⁴ Between 24 and up to 48 hours
- ☐ ⁵ More than 48 hours
- ☐ ⁶ Don't know or can't remember
- ☐ ⁷ I was not admitted to a ward

Section 10: Co-ordination of care

The questions in this section ask about the interactions between the teams of healthcare staff looking after you during your care and treatment and the support and care you may have received from your GP practice during this time.

Q32. How would you rate the co-ordination of your care (getting letters at the right time, doctors having the right notes and test results and so on)?

- ☐ ¹ Very good
- ☐ ² Good
- ☐ ³ Neither good nor poor
- ☐ ⁴ Poor
- ☐ ⁵ Very poor
- ☐ ⁶ Don't know or can't remember

Q33. Did the healthcare staff that you saw during your treatment have all the information that they needed about you?

- ☐ ¹ Yes, completely
- ☐ ² Yes, to some extent
- ☐ ³ No
- ☐ ⁴ Don't know or can't remember

Q34. As far as you know, was your GP informed of your cancer and your treatment?

- ☐ ¹ Yes, definitely
- ☐ ² Yes, to some extent
- ☐ ³ No
- ☐ ⁴ I do not have a regular GP
- ☐ ⁵ Don't know or can't remember

Q35. Did you get the support you needed from staff at your GP practice while you were having cancer treatment?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No, and I needed support
- ⁴ ☐ I have not needed support from staff at my GP practice
- ⁵ ☐ Don't know or can't remember

Q36. If you needed it, did the hospital staff make sure you had help at home and any equipment to manage daily tasks?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ This was not necessary

Q37. Were you given information about how to get financial help or other supports you may be eligible for (like subsidised travel and home care)?

- ¹ ☐ Yes
- ² ☐ No, and I would have liked this information
- ³ ☐ No, I didn't need this information
- ⁴ ☐ Don't know or can't remember

Section 11: Potential side effects

The questions in this section ask about the immediate and long-term side effects you may have experienced during and after your cancer treatment.

Immediate side effects are those that occur shortly after the start of treatment or during the course of treatment. Long-term side effects usually arise sometime after your cancer treatment ends.

Q38. Before you started your treatment(s), were the potential immediate side effects of your treatment(s) explained in a way you could understand?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ I didn't need an explanation
- ⁵ ☐ Don't know or can't remember

Q39. Were you offered practical advice and support in dealing with any immediate side effects of your treatment(s)?

- ¹ ☐ Yes, always
- ² ☐ Yes, sometimes
- ³ ☐ No
- ⁴ ☐ I didn't need practical advice or support
- ⁵ ☐ Don't know or can't remember

Q40. Before you started your treatment(s), were the potential long-term side effects of your treatment(s), including their impact on your day-to-day activities, explained in a way you could understand?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ I didn't need an explanation
- ⁵ ☐ Don't know or can't remember

Q41. Were you able to discuss options for managing the potential impact of any long-term side effects of your treatment(s) on your day-to-day activities?

- ☐ ¹ Yes, definitely
- ☐ ² Yes, to some extent
- ☐ ³ No, but I would have liked to
- ☐ ⁴ No, I didn't need to
- ☐ ⁵ Don't know or can't remember

Section 12: Living with and beyond cancer

The following section asks about your experience of the care you received once you finished your cancer treatment(s).

Q42. If your cancer treatment has finished, were you given a written summary that included information about the treatment(s) you received and follow-up care over the next 12 months? (This should be more than a list of medical appointments)

- ☐ ¹ My treatment hasn't finished → **Go to Q46**
- ☐ ² Yes, for all my treatments → **Go to Q43**
- ☐ ³ Yes, for some of my treatments → **Go to Q43**
- ☐ ⁴ No → **Go to Q43**
- ☐ ⁵ Don't know or can't remember → **Go to Q43**

Q43. Between your final treatment and first follow-up appointment, did the hospital staff looking after you provide the support you needed?

- ☐ ¹ Yes, definitely
- ☐ ² Yes, to some extent
- ☐ ³ No
- ☐ ⁴ Don't know or can't remember

Q44. Were you given information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if you had concerns?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ I did not want or need this information
- ⁵ ☐ Don't know or can't remember

Q45. Once your cancer treatment had finished, could you get support at home from community or voluntary services (for example public health nurses, paid carers, physiotherapists)?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ I didn't need support from community or voluntary services
- ⁵ ☐ Don't know or can't remember

Section 13: Overall care

The questions in this section ask you about your overall experience of care during your cancer treatment.

Q46. Did you have confidence and trust in the team of healthcare staff involved in your care?

- ¹ ☐ Yes, always
- ² ☐ Yes, sometimes
- ³ ☐ No

Q47. Did you experience any of the following problems when travelling to appointments relating to your cancer care? Tick all that apply.

- ¹ ☐ Access to suitable accommodation
- ² ☐ Access to suitable transport
- ³ ☐ Cost of accommodation
- ⁴ ☐ Cost of travel and parking
- ⁵ ☐ Lack of parking
- ⁶ ☐ Frequency of travel
- ⁷ ☐ Lack of information
- ⁸ ☐ Length of time spent waiting for your appointment(s)
- ⁹ ☐ Too unwell to travel
- ¹⁰ ☐ Another difficulty. Please describe:

- ¹¹ ☐ I had no difficulties

Q48. Overall, were you given enough privacy when being examined or treated?

- ¹ ☐ Yes, always
² ☐ Yes, sometimes
³ ☐ No
⁴ ☐ Don't know or can't remember

Q49. Overall, how would you rate your experience of the care that you received?

Please tick a box between 0 (very poor experience) and 10 (very good experience).

Very poor experience				Very good experience						
←				→						
0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Q50. Since your diagnosis, has anyone discussed with you whether there are any clinical trials relevant to your cancer that you could take part in (for example new treatments or additional tests)?

- ¹ ☐ Yes
² ☐ No, and I would have liked them to
³ ☐ No, I didn't want them to
⁴ ☐ Don't know or can't remember

Section 14: Patient safety

A patient safety incident is something that happened during your hospital care which caused you harm or put you at risk of harm. This could include (but is not limited to) an event such as:

- Being given (or almost given) the wrong medication
- Getting a test or treatment intended for another patient
- Getting the wrong diagnosis
- Having a fall while in hospital

The following section asks about your safety when receiving your cancer care and treatment.

Q51. Did you experience any patient safety incident(s) during your cancer care and treatment?

- ¹ ☐ Yes → **Go to Q52**
² ☐ No → **Go to Q53**
³ ☐ Don't know or can't remember → **Go to Q53**

Q52. If you experienced a patient safety incident, did a healthcare professional have a conversation with you to discuss what happened?

This type of conversation about a patient safety incident is usually called 'open disclosure'.

- ¹ ☐ Yes
² ☐ No
³ ☐ Don't know or can't remember

Section 15: Your condition

The following section asks for some information about your cancer diagnosis. This will help us to describe the participants in the survey.

Q53. How long ago were you diagnosed with cancer?

- ☐ ¹ Less than 6 months ago
- ☐ ² Between 6 and 12 months ago
- ☐ ³ Between 1 and 2 years ago
- ☐ ⁴ Between 2 and 5 years ago
- ☐ ⁵ More than 5 years ago
- ☐ ⁶ Don't know or can't remember

Q54. Had the cancer spread to other organs or parts of your body at the time you were first told you had cancer?

- ☐ ¹ Yes
- ☐ ² No
- ☐ ³ Don't know or can't remember
- ☐ ⁴ Doesn't apply to my type of cancer

Section 16: About you

The questions in the following section ask some general information about you. This will help us to describe the participants in the survey. These questions ask about your life and not specifically about your cancer diagnosis.

Q55. What is your ethnic or cultural background? Tick one box only

- ☐ ¹ White Irish
- ☐ ² Irish Traveller
- ☐ ³ Roma
- ☐ ⁴ Any other White background, please specify:
- ☐ ⁵ Black Irish
- ☐ ⁶ Black African
- ☐ ⁷ Any other Black background, please specify:
- ☐ ⁸ Asian Irish
- ☐ ⁹ Asian Indian
- ☐ ¹⁰ Chinese
- ☐ ¹¹ Any other Asian background, please specify:
- ☐ ¹² Arab
- ☐ ¹³ Mixed group / background, please specify:
- ☐ ¹⁴ Other group / background, please specify:

Q56. Do you currently have any of the following? Tick all that apply.

- ☐ ¹ A medical card
- ☐ ² A GP visit card
- ☐ ³ Private health insurance
- ☐ ⁴ None of the above
- ☐ ⁵ Don't know

Q57. Do you have any of the following on a long-term basis? Tick all that apply.

- ☐ ¹ Blindness or serious vision impairment
- ☐ ² Deafness or a serious hearing impairment
- ☐ ³ A condition that substantially limits one or more basic physical activities
- ☐ ⁴ An intellectual disability
- ☐ ⁵ Difficulty in learning, remembering or concentrating
- ☐ ⁶ Mental health, psychological or emotional condition
- ☐ ⁷ Difficulty in dressing, bathing or getting around inside the home
- ☐ ⁸ Difficulty in going outside the home alone
- ☐ ⁹ Difficulty in working or attending school or college
- ☐ ¹⁰ Difficulty in taking part in other activities
- ☐ ¹¹ Other disability, including chronic illness
- ☐ ¹² None of the above

Q58. Who was the main person or people who filled in this questionnaire?

- ☐ ¹ The person named on the front of the envelope
- ☐ ² The person named on the front of the envelope with the help of someone else
- ☐ ³ Someone acting on behalf of the person named on the front of the envelope

Section 17: Other comments

Please feel free to tell us more about your experience of care by answering the questions below. You can use the back page of the questionnaire if you need more space. Please do not share your name or address in your comments. Comments will be entered into a secure database after removing any information that could identify you.

This anonymised feedback will be looked at by HIQA, the HSE and the Department of Health to try to understand and improve patients' experiences of cancer care. Other researchers may also analyse anonymised data from this survey in the future, after all personal information that could identify you has been removed. We will give examples of feedback in the final survey reports to provide a fuller understanding of patients' experiences.

Q59. Was there anything particularly good about your care?

Q60. Was there anything that could be improved?

Thank you very much for taking part in this survey.

Please check that you have answered all of the questions that apply to you.

Please return this questionnaire in the Freepost envelope provided. No stamp is needed.

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