

# Cancer Patient Experience Survey

This survey is about your experiences of cancer care received in Scotland.

The responses you give will help improve cancer services and support.  
**All of the answers you provide will be entirely confidential.**

**Please read the enclosed letter for more information about this survey.**



If you would prefer, you may also complete this survey online:

**Go to [www.quality-health.co.uk/scc15](http://www.quality-health.co.uk/scc15)**

Or scan the QR Code with your tablet / smartphone



To do this you will need to enter the User name and Password which can be found on the letter which came with this survey.

## Instructions

The questions should be answered by the person named on the letter which came with the survey. A friend or carer can help you complete the survey but the answers should be yours not theirs.

The survey takes around 20 minutes to complete. Please answer all questions, unless the instructions ask you to skip a question. For each question, please place a tick in the box next to the answer that most closely matches your own experience. For example, if your answer is yes, write in a tick as below:

Yes

No

Don't worry if you make a mistake. Simply cross it out and tick the correct answer.



**Helpline**  
**0800 783 1775**  
**Monday – Friday**  
**9am – 5pm**

Please return in the envelope provided or to:

Quality Health  
FREEPOST RSKS-ZERR-UAGY  
Unit 1, Holmewood Business Park  
Chesterfield Road  
Holmewood  
Chesterfield  
S42 5US

## SEEING YOUR GP

*These questions are about what happened before you went into hospital about cancer.*

1. Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?
  - 1  **None** – I went straight to hospital
  - 2  **None** – I went to hospital following a cancer screening appointment
  - 3  I saw my GP **once**
  - 4  I saw my GP **twice**
  - 5  I saw my GP **3 or 4** times
  - 6  I saw my GP **5 or more** times
  - 7  Don't know / can't remember
2. How do you feel about the length of time you had to wait before your **first appointment with a hospital doctor**?
  - 1  I was seen as soon as I thought was necessary
  - 2  I should have been seen a bit sooner
  - 3  I should have been seen a lot sooner
3. How long was it from the time you first thought something might be wrong with you until you first saw a GP or other doctor?
  - 1  Less than 3 months
  - 2  3 - 6 months
  - 3  6 - 12 months
  - 4  More than 12 months
  - 5  Don't know / can't remember

## DIAGNOSTIC TESTS

4. Have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan?

- 1  Yes → **Go to Q5**
- 2  No → **Go to Q9**

*Thinking about the LAST time you had a diagnostic test for your cancer....*

5. Beforehand, did you have all the information you needed about your test? **(Tick ALL that apply)**
  - 1  Yes
  - 2  No, I would have liked more **written** information
  - 3  No, I would have liked more **verbal** information
  - 4  I did not need / want any information
  - 5  Don't know / can't remember
6. Overall, how did you feel about the length of time you had to wait for your test to be done?
  - 1  It was about right
  - 2  It was a little too long
  - 3  It was much too long
  - 4  Don't know / can't remember
7. Were the results of the test explained in a way you could understand?
  - 1  Yes, completely
  - 2  Yes, to some extent
  - 3  No, I did not understand the explanation
  - 4  I did not have an explanation but would have liked one
  - 5  I did not need an explanation
  - 6  Don't know / can't remember

8. Did the test take place at the hospital named on the letter that came with this survey?

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

## FINDING OUT WHAT WAS WRONG WITH YOU

9. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?

- 1  Yes
- 2  No
- 3  It was not necessary
- 4  I was told by phone or letter
- 5  Don't know / can't remember

10. How do you feel about the way you were told you had cancer?

- 1  It was done sensitively
- 2  It should have been done **a bit** more sensitively
- 3  It should have been done **a lot** more sensitively

11. Did you understand the explanation of what was wrong with you?

- 1  Yes, I completely understood it
- 2  Yes, I understood some of it
- 3  No, I did not understand it
- 4  Don't know / can't remember

12. When you were told you had cancer, were you given **written** information about the type of cancer you had?

- 1  Yes, and it was **easy** to understand
- 2  Yes, but it was **difficult** to understand
- 3  No, I was not given written information about the type of cancer I had
- 4  I did not need written information
- 5  Don't know / can't remember

If there is anything else you would like to tell us about the lead-up to your cancer diagnosis, or the way you found out you had cancer, please do so here.

## DECIDING THE BEST TREATMENT FOR YOU

13. Before your cancer treatment started, were your treatment options explained to you?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  There was only one type of treatment that was suitable for me
- 5  Don't know / can't remember

14. Were the possible side effects of treatment(s) explained in a way you could understand?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, side effects were not explained
- 4  I did not need an explanation
- 5  Don't know / can't remember

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

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, I was not offered any practical advice or support
- 4  Don't know / can't remember

16. Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, future side effects were not explained
- 4  I did not need an explanation
- 5  Don't know / can't remember

17. Were you involved as much as you wanted to be in decisions about your care and treatment?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would like to have been more involved
- 4  Don't know / can't remember

If there is anything else you would like to tell us about the way decisions were made about your treatment please do so here.

## CLINICAL NURSE SPECIALIST

*A Clinical Nurse Specialist is a specialist cancer nurse who helps you get the right care and gives you help and advice on coping with cancer.*

18. Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?

- 1  Yes → Go to Q19
- 2  No → Go to Q21
- 3  Don't know / can't remember → Go to Q21

19. How easy or difficult has it been for you to contact your Clinical Nurse Specialist?

- 1  Very easy
- 2  Quite easy
- 3  Neither easy nor difficult
- 4  Quite difficult
- 5  Very difficult
- 6  I did not try to contact my Clinical Nurse Specialist

20. When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?

- 1  All or most of the time  
 2  Some of the time  
 3  Rarely or never  
 4  I have not asked any questions

## SUPPORT FOR PEOPLE WITH CANCER

21. Did hospital staff give you information about support or self-help groups for people with cancer?

- 1  Yes  
 2  No, but I would have liked information  
 3  It was not necessary  
 4  Don't know / can't remember

22. Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?

- 1  Yes  
 2  No, but I would have liked a discussion or information  
 3  It was not necessary / relevant to me  
 4  Don't know / can't remember

23. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?

- 1  Yes  
 2  No, but I would have liked information  
 3  It was not necessary  
 4  Don't know / can't remember

If there is anything else you would like to tell us about the support you received (including from a clinical nurse specialist) please do so here.

## OPERATIONS

24. Have you had an operation (such as removal of a tumour or lump) for your cancer?

- 1  Yes → Go to Q25  
 2  No → Go to Q28

***Thinking about the LAST time you went into hospital for an operation for your cancer ...***

25. Beforehand, did you have all the information you needed about your operation? (**Tick ALL that apply**)

- 1  Yes  
 2  No, I would have liked more **written** information  
 3  No, I would have liked more **verbal** information  
 4  I did not need / want information  
 5  Don't know / can't remember

26. After the operation, did a member of staff explain how it had gone in a way you could understand?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No, but I would have liked an explanation
- 4  I did not need an explanation

27. Did the operation take place at the hospital named on the letter that came with this survey?

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

## HOSPITAL CARE AS AN INPATIENT

28. Have you had an operation or stayed overnight **for cancer care**?

- 1  Yes → **Go to Q29**
- 2  No → **Go to Q42**

***Thinking about the LAST time you had an operation or stayed overnight for cancer care...***

29. Did groups of **doctors and nurses** talk in front of you as if you weren't there?

- 1  Yes, often
- 2  Yes, sometimes
- 3  No

30. Did you have confidence and trust in the **doctors** treating you?

- 1  Yes, in all of them
- 2  Yes, in some of them
- 3  No, in none of them

31. If your family or someone else close to you wanted to talk to a **doctor**, were they able to?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  No family or friends were involved
- 5  My family did not want to talk to a doctor
- 6  I did not want my family or friends to talk to a doctor

32. Did you have confidence and trust in the ward **nurses** treating you?

- 1  Yes, in all of them
- 2  Yes, in some of them
- 3  No, in none of them

33. In your opinion, were there enough **nurses** on duty to care for you in hospital?

- 1  There were always or nearly always enough on duty
- 2  There were sometimes enough on duty
- 3  There were rarely or never enough on duty

34. While you were in hospital did the **doctors and nurses** ask you what name you prefer to be called by?

- 1  Yes, all of them did
- 2  Only some of them did
- 3  None of them did

35. Were you given enough privacy when discussing your condition or treatment?

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

36. During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?
- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  I had no worries or fears
37. Do you think the hospital staff did everything they could to help control your pain?
- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  I did not have any pain
38. Overall, did you feel you were treated with respect and dignity while you were in hospital?
- 1  Yes, always
- 2  Yes, sometimes
- 3  No
39. Were you given clear **written** information about what you should or should not do after leaving hospital?
- 1  Yes
- 2  No
- 3  Don't know / can't remember
40. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?
- 1  Yes
- 2  No
- 3  Don't know / can't remember

41. Did your overnight stay or operation take place at the hospital named on the letter that came with this survey?

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

If there is anything else you would like to tell us about the care you received when you had an operation or stayed overnight in hospital, please do so here.

### HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT

42. Have you been treated as an outpatient or day case **for cancer care**?
- 1  Yes → **Go to Q43**
- 2  No → **Go to Q46**

***Thinking about the LAST time you attended hospital as a day patient or outpatient for cancer care ...***

43. While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?
- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  I did not have any worries or fears

44. The **last** time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?

- 1  Yes
- 2  No
- 3  I didn't have an appointment with a cancer doctor
- 4  Don't know / can't remember

45. The last time you attended hospital as a day case or outpatient, was this at the hospital named on the letter that came with this survey?

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

If there is anything else you would like to tell us about the day patient/outpatient care you received please do so here.

## RADIOTHERAPY AND CHEMOTHERAPY

46. Have you had radiotherapy treatment?

- 1  Yes → **Go to Q47**
- 2  No → **Go to Q50**

47. Beforehand, did you have all of the information you needed about your radiotherapy treatment?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  I did not need any information

48. Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  It is too early to know if my radiotherapy is working
- 5  I did not need any information

49. Did your radiotherapy treatment take place at the hospital named on the letter that came with this survey?

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

50. Have you had chemotherapy treatment?

- 1  Yes → **Go to Q51**
- 2  No → **Go to Q54**



51. Beforehand, did you have all of the information you needed about your chemotherapy treatment?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  I did not need any information

52. Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  It is too early to know if my chemotherapy is working
- 5  I did not need any information

53. Did your chemotherapy treatment take place at the hospital named on the letter that came with this survey?

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

If there is anything else you would like to tell us about your chemotherapy / radiotherapy treatment please do so here.

## HOME CARE AND SUPPORT

54. Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  No family or friends were involved
- 5  My family or friends did not want or need information
- 6  I did not want my family or friends to be involved

55. **During** your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  I did not need help from health or social services
- 5  Don't know / can't remember

56. Once your cancer treatment **finished** were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  I did not need help from health or social services
- 5  I am still having treatment
- 6  Don't know / can't remember

## CARE FROM YOUR GENERAL PRACTICE

57. As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?

1  Yes

2  No

3  Don't know / can't remember

58. Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?

1  Yes, definitely

2  Yes, to some extent

3  No, they could have done more

4  My general practice was not involved

## YOUR OVERALL NHS CARE

59. Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?

1  Yes, always

2  Yes, most of the time

3  Yes, some of the time

4  No, never

5  Don't know / can't remember

60. Have you been given a care plan? *A care plan is a document that sets out your needs and goals for caring for your cancer. It is an agreement or plan between you and your health professional to help meet those goals.*

1  Yes

2  No

3  I do not know/understand what a care plan is

4  Don't know / can't remember

61. Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc)?

1  Very good

2  Good

3  Neither good nor bad

4  Quite bad

5  Very bad

6  Don't know / can't remember

62. Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?

1  Much too long

2  A little too long

3  About right

4  Don't know / can't remember

63. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?

1  Yes

2  No

3  No, but I would have liked them to

4  Don't know / can't remember

64. Overall, how would you rate your care?  
(Please circle a number)

Very poor

Very good

0 1 2 3 4 5 6 7 8 9 10

If there is anything else you would like to say about your experiences of cancer care please do so here.

## YOUR CONDITION

*We would like to understand a little bit more about your cancer and how you are now. Please answer these questions about the cancer that was treated at the hospital named on the covering letter*

65. How long is it since you were first treated for **this cancer**?

- 1  Less than 1 year
- 2  1 to 5 years
- 3  More than 5 years
- 4  Don't know / can't remember

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

- 1  Yes → **Go to Q68**
- 2  No → **Go to Q67**
- 3  Don't know → **Go to Q68**
- 4  Does not apply to my type of cancer → **Go to Q68**

67. Which of the following applies?

- 1  My cancer has been taken out / treated without any sign of further problem
- 2  My cancer was taken out / treated without any sign of further problem, but has since come back/spread to other parts of my body
- 3  None of the above options apply to my type of cancer
- 4  I would prefer not to say
- 5  I don't know

## ABOUT YOU

*If you are helping someone to complete this questionnaire, please make sure this information is the patient's not your own.*

68. What was your age on your last birthday?

69. Are you male or female?

- 1  Male
- 2  Female

70. Which of the following best describes your sexual orientation? (**Tick one box only**)

- 1  Heterosexual / straight
- 2  Bisexual
- 3  Gay or Lesbian
- 4  Other

71. What is your ethnic group?

*(Tick **ONE** box which **best describes** your ethnic group)*

- 1  White
- 2  Mixed or multiple ethnic groups
- 3  Asian, Asian Scottish or Asian British
- 4  African, Caribbean or Black
- 5  Other ethnic group

72. What is your **main** employment status?  
(If on maternity or sick leave answer in relation to your usual employment status)

- 1  Work full time
- 2  Work part time
- 3  In full time education or training
- 4  Retired
- 5  Unemployed / looking for work
- 6  Don't work due to illness or disability
- 7  Other

73. Do you have any of the following?  
*Please tick **ALL** that apply*

- 1  Deafness or severe hearing impairment
- 2  Blindness or severe vision impairment
- 3  A physical disability
- 4  A learning disability
- 5  A mental health condition
- 6  Chronic pain lasting at least 3 months
- 7  Another long-term condition
- 8  None of the above

74. Could NHS Scotland, the Scottish Government, or Macmillan Cancer Support send you a survey in the future to ask about cancer and cancer care?

- 1  Yes, and I understand that this does **NOT** mean that I would have to take part in the survey
- 2  No, I would prefer you not to contact me again

We would like your permission to add your survey responses to other information held about your health and care by NHS Scotland (e.g. about the kind of treatment you have had for your cancer or whether or not you have any other health conditions). Your information will be used only for research and it will not be possible to identify you individually.

If you give your permission to add your survey results to other health and care information held about you, it will not be shared with the people who look after you and will in no way affect your current or future treatment or care.

75. Do you give your permission for NHS Scotland Statisticians to add your survey results to other information about your health and care for the purpose of this cancer patient experience survey?

- 1  Yes
- 2  No

76. Do you give your permission for NHS Scotland Statisticians to add your survey results to other information about your health and care for the purposes of other future research?

The future research would be conducted by NHS Scotland, the Scottish Government, Macmillan Cancer Support, or an organisation working on their behalf.

- 1  Yes
- 2  No