

Cancer Patient Experience Survey

This survey is about your experiences of cancer care received in Wales. **Your answers will be entirely confidential. Taking part is voluntary.** This questionnaire has been printed in **both English and Welsh. Please complete it in your language of choice.**

Instructions

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. Please **do not** write your name or address anywhere on the questionnaire.



If you would prefer, you can fill in this survey **online** in English or Welsh at **www.experiencesurvey.org.uk**.

To do this you will need to enter this ID:



If you have any queries about the questionnaire, please call the **FREEPHONE helpline** number on **0808 801 0678**

Open: 24/7

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate collective statistics about the care and treatment people receive. The results will be used to measure and improve the quality of healthcare services. 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.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Welsh Government to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service and other NHS databases can be held and used by an organisation contracted to the Welsh Government to analyse the data
- Your responses to the survey can be held and used by the NHS Welsh Cancer Intelligence and Surveillance Unit and securely linked to information about you held in other databases to help improve services

Your personal information will be handled securely and anonymised after analysis and before any publication. Your personal information will not be released by the Welsh Government or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest. You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

Thank you for your time.

BEFORE YOUR DIAGNOSIS

These questions are about what happened before you found out you had cancer.

1. 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 I did not think something was wrong with me until I was told
- 6 Don't know / can't remember

2. 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 I saw my GP **once**
- 2 I saw my GP **twice**
- 3 I saw my GP **3 or 4** times
- 4 I saw my GP **5 or more** times
- 5 I went straight to hospital following a cancer screening appointment
- 6 I went straight to hospital via Accident & Emergency
- 7 Don't know / can't remember

3. When you first told your GP or hospital doctor about your symptoms, do you feel they took your symptoms seriously?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No
- 4 I did not have any symptoms
- 5 Don't know / can't remember

4. 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

5. Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?

- 1 My health got worse
- 2 My health got better
- 3 My health stayed about the same

6. In the last 12 months, have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan?

- 1 Yes → **Go to Q7**
- 2 No → **Go to Q11**

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

7. Did the test(s) take place at the hospital named on the letter that came with this survey?

- 1 Yes
- 2 No, at another NHS hospital in Wales
- 3 No, at a private hospital/centre in Wales
- 4 No, somewhere outside Wales
- 5 Don't know / can't remember

8. Beforehand, did a member of staff explain what would be done during the test(s) to you?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, but I would have liked an explanation
- 4 I did not need an explanation
- 5 Don't know / can't remember

9. Beforehand, were you given **written** information about your test(s)?

- 1 Yes, and it was **easy** to understand
- 2 Yes, but it was **difficult** to understand
- 3 No, I would have liked written information about the test(s)
- 4 I did not need written information
- 5 Don't know / can't remember

10. Were the **results** of the test(s) explained in a way you could understand?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, I did not understand the explanation
- 4 No, but I would have liked an explanation
- 5 I did not need an explanation
- 6 Don't know / can't remember

FINDING OUT YOU HAD CANCER

11. 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

12. 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 Can't remember

13. 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

DECIDING THE BEST TREATMENT AND/OR CARE FOR YOU

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

- 1 Yes
- 2 No, but I would have liked a choice
- 3 There was only one type of treatment that was suitable for me
- 4 Not sure / can't remember

15. 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 Not sure / can't remember

16. 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 Not sure / can't remember

17. Before you started your treatment, were you given **written** information about the side effects of your treatment(s)?

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

18. Before you started your treatment, 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 Not sure / can't remember

KEY WORKER

The next few questions are about Key Workers.

Key Worker is the title given to a health professional who you can contact for advice and information and who will coordinate your care. This person may change depending on where you are in your cancer care and treatment. They could be your Clinical Nurse Specialist or another health care professional.

19. Were you given the name and contact details of your Key Worker?

- 1 Yes → **Go to Q20**
- 2 No → **Go to Q22**
- 3 Don't know / not sure → **Go to Q22**

20. How easy is it for you to contact your Key Worker?

- 1 Easy
- 2 Sometimes easy, sometimes difficult
- 3 Difficult
- 4 I have not tried to contact her/him

21. When you have important questions to ask, how often does your Key Worker help you get answers to your questions?

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

CLINICAL NURSE SPECIALIST

The next few questions are about Clinical Nurse Specialists.

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

22. Did your care include access to a Clinical Nurse Specialist?

- 1 Yes, and this was my Key Worker → **Go to Q24**
- 2 Yes, but this was not my Key Worker → **Go to Q23**
- 3 No, I did not have a Clinical Nurse Specialist as part of my care team → **Go to Q26**
- 4 Don't know / not sure → **Go to Q26**

23. How easy is it for you to contact your Clinical Nurse Specialist?

- 1 Easy
- 2 Sometimes easy, sometimes difficult
- 3 Difficult
- 4 I have not tried to contact her/him

24. When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?

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

25. Did your Clinical Nurse Specialist provide you with the information you needed to make informed decisions about your treatment and care?

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

SUPPORT FOR PEOPLE WITH CANCER

Thinking about when your cancer treatment first started ...

26. How much information about support or self-help groups did hospital staff give you?

- 1 Not enough
- 2 The right amount
- 3 Too much
- 4 I was not given any information
- 5 Don't know / can't remember

27. During your care, were you told about voluntary or charity support?

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

28. 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, completely
- 2 Yes, to some extent
- 3 No
- 4 Don't know / can't remember

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

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

OPERATIONS

30. During the last 12 months, have you had an operation for your cancer (such as removal of a tumour or lump)?

- 1 Yes → Go to Q31
- 2 No → Go to Q35

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

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

- 1 Yes
- 2 No, at another NHS hospital in Wales
- 3 No, at a private hospital/centre in Wales
- 4 No, somewhere outside Wales
- 5 Don't know / can't remember

Please remember you are thinking about the LAST time you went into hospital for an operation for your cancer...

32. Before you had your operation, did a member of staff explain what would be done during the operation?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, but I would have liked an explanation
- 4 I did not need an explanation
- 5 Don't know / can't remember

33. Beforehand, were you given **written** information about your operation?

- 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 my operation
- 4 I did not need written information
- 5 Don't know / can't remember

34. 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

HOSPITAL CARE AS AN INPATIENT

35. During the last 12 months, have you had an operation or stayed overnight **for cancer care**?

- 1 Yes → **Go to Q36**
- 2 No → **Go to Q52**

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

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

- 1 Yes
- 2 No, at another NHS hospital in Wales
- 3 No, at a private hospital/centre in Wales
- 4 No, somewhere outside Wales
- 5 Don't know / can't remember

37. Overall, while you were in hospital, were you treated with dignity and respect?

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

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

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

39. While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different?

- 1 Often
- 2 Sometimes
- 3 Only once
- 4 Never

40. Were you able to discuss any worries or fears with staff during your hospital visit?

- 1 As much as I wanted
- 2 Most of the time
- 3 Some of the time
- 4 Not at all, but would have liked to
- 5 I did not have any worries or fears

Please remember you are thinking about the LAST time you had an operation or stayed overnight for cancer care...

41. When you had important questions to ask a doctor or nurse, how often did you get answers that you could understand?

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

42. Did your family or someone else close to you have enough opportunity to talk to a healthcare professional?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 No family or friends were involved

43. 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

44. 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

45. How many minutes after you used the call button did it usually take before you got the help you needed?

- 1 0 minutes / right away
- 2 1-2 minutes
- 3 3-5 minutes
- 4 More than 5 minutes
- 5 I never got help when I used the call button
- 6 I never used the call button

46. Do you think doctors and nurses communicated effectively with you during your hospital stay?

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

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

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

48. Were you given enough privacy when being examined or treated?

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

49. Do you think the hospital staff did everything they could to help control your pain?

- 1 All of the time
- 2 Some of the time
- 3 Not at all
- 4 I did not have any pain

50. Were you given clear written information about what you should or should not do after leaving hospital?

- 1 Yes
- 2 No
- 3 I did not need written information
- 4 Can't remember

51. 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

OUTPATIENTS / DAY CASE APPOINTMENTS

52. In the last 12 months, have you had an outpatients or day case appointment for your cancer?

- 1 Yes → Go to Q53
2 No → Go to Q56

Thinking about the LAST time you attended hospital as an outpatient or day case for cancer care ...

53. 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, at another NHS hospital in Wales
3 No, at a private hospital/centre in Wales
4 No, somewhere outside Wales
5 Don't know / can't remember

54. While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?

- 1 Yes, definitely
2 Yes, to some extent
3 No, they could have done more
4 I did not have any pain

55. While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?

- 1 Yes, definitely
2 Yes, to some extent
3 No, I would have liked more support
4 I did not need emotional support from staff

RADIOTHERAPY / CHEMOTHERAPY

56. Have you had radiotherapy treatment?

- 1 Yes → Go to Q57
2 No → Go to Q59

57. Thinking of the **last** time you had radiotherapy treatment, was this at:

- 1 Glan Clwyd Hospital
2 Singleton Hospital
3 Velindre Cancer Centre
4 A private hospital/centre in Wales
5 Somewhere outside Wales
6 Don't know / can't remember

Thinking about the LAST time you had radiotherapy treatment...

58. Did hospital staff do everything possible to control the side effects of radiotherapy?

- 1 Yes, definitely
2 Yes, to some extent
3 No, they could have done more
4 I have not had any side effects from radiotherapy

59. Have you had chemotherapy treatment?

- 1 Yes → Go to Q60
2 No → Go to Q62

Thinking about the LAST time you had chemotherapy treatment...

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

- 1 Yes
2 No, at another NHS hospital in Wales
3 No, at a private hospital/centre in Wales
4 No, somewhere outside Wales
5 Don't know / can't remember

Please remember you are thinking about the LAST time you had chemotherapy treatment...

61. Did hospital staff do everything possible to control the side effects of chemotherapy?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, they could have done more
- 4 I have not had any side effects from chemotherapy

ARRANGING HOME SUPPORT

Thinking about the LAST time you left the hospital named on the covering letter following care for your cancer...

62. 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

63. Were you offered practical advice and support in dealing with the side effects of your treatment(s) at home (such as physical activity advice, how to manage diet and fatigue)?

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

64. After leaving hospital, were you given enough care and help from your GP and the GP surgery?

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

65. As far as you know, did your GP have all the information they needed about your care after leaving hospital?

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

66. After leaving hospital, were you given enough care and help 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
- 5 Don't know / can't remember

YOUR OVERALL NHS CARE

67. Were you offered the opportunity to discuss your needs and concerns in order to put together a care plan?

(This is a discussion to find out as much as possible about your concerns and/or needs, be they physical, emotional, mental, spiritual, social or environmental to put together a care plan to give you the help you need.)

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

68. Have you been offered a written care plan?

(A written care plan is a document that sets out your needs and goals for caring for you and your cancer. It is an agreement or plan between you and your health professional to help meet those goals.)

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

69. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research (e.g. clinical trials)?

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

70. Since your diagnosis, have the different professionals treating and caring for you worked 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

71. 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

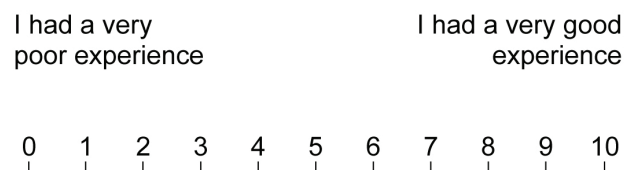
72. During your care, did you receive the information you needed in your preferred language?

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

73. Sometimes people with cancer feel they are treated as “a set of cancer symptoms”, rather than a whole person. In your NHS care over the last year did you feel like that?

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

74. Overall how would you rate your care? **(Please circle a number)**



YOUR CONDITION

We would like to understand a little 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.

75. 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

76. Is this the first time you have been treated for cancer?

- 1 Yes, this is the first time I have been treated for cancer → **Go to Q78**
- 2 No, I have been treated for the same type of cancer before but it has now come back → **Go to Q77**
- 3 No, I have been treated for a different type of cancer before → **Go to Q78**
- 4 Don't know → **Go to Q78**

77. When your cancer came back did it:

- 1 Come back only in the same place as before
- 2 Spread to somewhere else in the body

78. How has your cancer responded to treatment?

- 1 My cancer has responded fully to treatment (I have no signs or symptoms of cancer)
- 2 My cancer has been treated but is still present
- 3 My cancer has not been treated at all
- 4 My cancer has come back after it was originally treated
- 5 My original cancer responded but I now have a new cancer
- 6 I am not certain what is happening with my cancer

ABOUT YOU

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

79. What year were you born?

(Please write in) e.g.

1	9	4	4
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80. Are you male or female?

- 1 Male
- 2 Female
- 3 Transgender
- 4 Prefer not to say

81. Which of the following best describes how you think of yourself? (Tick one box only)

- 1 Heterosexual / straight (opposite sex)
- 2 Bisexual (both sexes)
- 3 Gay or lesbian (same sex)
- 4 Other
- 5 Prefer not to answer

82. What is your **main** employment status?

(If on maternity or sick leave answer in relation to your usual employment status.)

- 1 Full time employment
- 2 Part time employment
- 3 Homemaker
- 4 Student (in education)
- 5 Retired
- 6 Unemployed – and seeking work
- 7 Unemployed – unable to work for health reasons
- 8 Other

83. Do you have any of the following long-standing conditions? (Tick all that apply)

- 1 Deafness or severe hearing impairment
- 2 Blindness or partially sighted
- 3 A long-standing physical condition
- 4 A learning disability
- 5 A mental health condition
- 6 A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy
- 7 No, I do not have a longstanding condition

84. Could we send you a survey in the future to ask about your health and healthcare?

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

85. To which of these ethnic groups would you say you belong? (Tick **ONE** only)

a. WHITE

- 1 Welsh / English / Scottish / Northern Irish / British
- 2 Irish
- 3 Gypsy or Irish Traveller
- 4 Any other White background (Please write in box)

b. MIXED / MULTIPLE ETHNIC GROUPS

- 5 White and Black Caribbean
- 6 White and Black African
- 7 White and Asian
- 8 Any other Mixed / Multiple ethnic background (Please write in box)

c. ASIAN OR ASIAN BRITISH

- 9 Indian
- 10 Pakistani
- 11 Bangladeshi
- 12 Chinese
- 13 Any other Asian background (Please write in box)

d. BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH

- 14 Caribbean
- 15 African
- 16 Any other Black / African / Caribbean background (Please write in box)

e. OTHER ETHNIC GROUP

- 17 Arab
- 18 Any other ethnic group (Please write in box)

OTHER COMMENTS

If there is anything else you would like to tell us about your experiences as a cancer patient in Wales, please do so here.

Please note that the comments you provide in the box below will be looked at in full by the Welsh Government, Macmillan, Local Health boards and researchers analysing the data. We will remove any information that could identify you before publishing any of your feedback.

Was there anything particularly good about your care?

Was there anything that could be improved?

Any other comments?