

## Scottish Cancer Patient Experience Survey

Please help us to understand and improve cancer services and support in your area.

Your views are very important to us. They help us to understand more about the quality of cancer services in your area and what needs to be improved.

Taking part is **voluntary** and your responses will be completely **confidential**. None of the health care professionals involved in your care will know whether or not you have responded.

Responses will be analysed, with national and local level results published in **Spring 2019**. For more information on how your responses to this survey will be used, including additional comments, please see our **Privacy Notice** at [www.gov.scot/CancerSurveyPrivacyNotice](http://www.gov.scot/CancerSurveyPrivacyNotice).

Please use blue or black ink and don't worry if you make a mistake, simply cross it out and tick the correct answer.

For more information about this survey, please read the enclosed letter or visit [www.gov.scot/CancerSurvey](http://www.gov.scot/CancerSurvey).



**Helpline**

XXXX XXX XXXX

Monday to Friday

### 1. Getting diagnosed

**Q1** Before you were told you needed to go to hospital about cancer, how many times did you see a healthcare professional at your GP Practice about the health problem caused by cancer?

1  Once → **Go to Q2**

4  5 or more times → **Go to Q2**

2  Twice → **Go to Q2**

5  I did not see anyone at my GP Practice → **Go to Q4**

3  3 or 4 times → **Go to Q2**

6  Don't know / can't remember → **Go to Q2**

**Q2** How long was it from the time you first thought something might be wrong with you until you first contacted a healthcare professional at your GP Practice?

1  Less than 3 months

4  More than 12 months

2  3 to 6 months

5  Don't know / can't remember

3  6 to 12 months

**Q3** 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

**Q4** Think about the **first time** you had a diagnostic test for cancer, such as an endoscopy, biopsy, mammogram or scan. Knowing what you know now, did you have all the information you needed about your test beforehand?

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

**Q5** Were the results of your **first** diagnostic 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 I would have liked one
- 5  I did not need an explanation
- 6  Don't know / can't remember
- 

**Q6** Did your **first** diagnostic test take place at the hospital named on the survey letter?

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

## 2. Finding out about your cancer

**Q7** 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      3  It was not necessary      5  Don't know / can't remember
- 2  No      4  I was told by phone or letter
- 

**Q8** 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
- 

**Q9** Did you understand the explanation of what was wrong with you?

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

**Q10** 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      4  I did not need / want written information  
2  Yes but it was **difficult** to understand      5  Don't know / can't remember  
3  No, I was not given written information about the type of cancer I had
- 

**Q11** 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.

### 3. Deciding the best treatment for you

**Q12** Before your treatment started, were your treatment options explained to you?

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

**Q13** Were you involved in discussions with healthcare professionals about the right treatment options for you? This may have included the option of not treating your cancer.

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

**Q14** Were the possible side effects of treatment(s) explained in a way you could understand?

- |  |  |
|--|--|
| 1 <input type="checkbox"/> Yes, definitely                           | 4 <input type="checkbox"/> I did not need an explanation |
| 2 <input type="checkbox"/> Yes, to some extent                       | 5 <input type="checkbox"/> Don't know / can't remember   |
| 3 <input type="checkbox"/> No, but I would have liked an explanation |  |
- 

**Q15** Were you offered practical advice and support in dealing with the side effects of your treatment(s)?

- |  |  |
|--|--|
| 1 <input type="checkbox"/> Yes, definitely     | 3 <input type="checkbox"/> No, I was not offered any practical advice or support |
| 2 <input type="checkbox"/> Yes, to some extent | 4 <input type="checkbox"/> Don't know / can't remember                           |
- 

**Q16** 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 <input type="checkbox"/> Yes, definitely                           | 4 <input type="checkbox"/> I did not need an explanation |
| 2 <input type="checkbox"/> Yes, to some extent                       | 5 <input type="checkbox"/> Don't know / can't remember   |
| 3 <input type="checkbox"/> No, but I would have liked an explanation |  |
- 

**Q17** Were you involved as much as you wanted to be in decisions about your care and treatment?

- |  |  |
|--|--|
| 1 <input type="checkbox"/> Yes, definitely     | 3 <input type="checkbox"/> No, but I would have liked to have been more involved |
| 2 <input type="checkbox"/> Yes, to some extent | 4 <input type="checkbox"/> Don't know / can't remember                           |
- 

**Q18** If there is anything else you would like to tell us about the way decisions were made about your treatment, please do so here.

## 4. Operations, Radiotherapy and Chemotherapy

**Q19** Have you had an operation, such as removal of a tumour or lump, for your cancer?

- 1  Yes → **Go to Q20**      2  No → **Go to Q24**
- 

**Q20** Think about the **last time** you went into hospital for an operation for your cancer. Knowing what you know now, did you have all the information you needed about your operation beforehand?

- 1  Yes  
2  No, I would have liked more **written** information  
3  No, I would have liked more **verbal** information  
4  No, I would have liked more **written and verbal** information  
5  I did not need / want any information
- 

**Q21** After the operation, did a member of staff explain how it had gone in a way you could understand?

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

**Q22** Were you given clear **written** information about what you should or should not do after the operation?

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

**Q23** Did the operation take place at the hospital named on the survey letter?

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

**Q24** Have you had radiotherapy treatment?

- 1  Yes, at the hospital named on the survey letter → **Go to Q25**  
2  Yes, at a **different** hospital to the one named on the survey letter → **Go to Q25**  
3  No → **Go to Q26**
- 

**Q25** Knowing what you know now, did you have all the information you needed about your radiotherapy treatment beforehand?

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

**Q26** Have you had chemotherapy treatment?

- 1  Yes, at the hospital named on the survey letter → **Go to Q27**  
2  Yes, at a **different** hospital to the one named on the survey letter → **Go to Q27**  
3  No → **Go to Q28**

**Q27** Knowing what you know now, did you have all the information you needed about your chemotherapy treatment beforehand?

1  Yes, completely

3  No

2  Yes, to some extent

4  I did not need any information

**Q28** If there is anything else you would like to tell us about your operation / radiotherapy / chemotherapy treatment, please do so here.

## 5. Hospital Care

For this section, please think about the **last time** you received **any hospital treatment for your cancer**, either as an inpatient or an outpatient / day case.

**Q29** Thinking about the healthcare professionals you came into contact with, how much do you agree or disagree with each of the following statements? *Please tick **one** box on each line. If a statement is not applicable, please leave that line blank.*

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
They spent enough time with me	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
They listened to me if I had any questions or concerns	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
They discussed my condition and treatment with me in a way I could understand	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
They gave me the opportunity to involve the people that matter to me	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
They helped me to feel in control of my treatment/care	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
They talked in front of me as if I wasn't there	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

**Q30** The **last time** you received hospital treatment for your cancer, did the healthcare professionals caring for you call you by your preferred name?

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

**Q31** Were you given enough privacy when discussing your condition or treatment?

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

**Q32** Did a healthcare professional 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
- 

**Q33** Did this experience take place at the hospital named on the survey letter?

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

**Q34** If there is anything else you would like to tell us about the care you received when you were in hospital for cancer care, please do so here.

## 6. Support from Health and Social Services

**Q35** 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.

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

- 1  Yes → **Go to Q36**      3  Don't know / can't remember → **Go to Q38**  
2  No → **Go to Q38**
- 

**Q36** How easy or difficult has it been for you to contact your Clinical Nurse Specialist?

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

**Q37** 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      3  Rarely or never  
2  Some of the time      4  I have not asked any questions
- 

**Q38** Do you think your GP Practice did everything they could to support you while you were having cancer treatment?

- 1  Yes, definitely      3  No, they could have done more  
2  Yes, to some extent      4  My GP Practice was not involved
- 

**Q39** **During** your cancer treatment, have you been given enough care and support from health or social services, for example district nurses, home carers or physiotherapists?

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

**Q40** Once your cancer treatment **finished** were you given enough care and support from health or social services?

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

## 7. Other Support

**Q41** Did healthcare professionals discuss with you or give you information about the impact cancer could have on your day-to-day activities?

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

**Q42** Did healthcare professionals give you information about support or self-help groups for people with cancer?

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

**Q43** Did healthcare professionals give you information about how to get financial help or any benefits you might be entitled to?

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

**Q44** Did healthcare professionals 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  This does not apply to me  
5  Don't know / can't remember
- 

**Q45** Do you feel you have been supported emotionally and psychologically by healthcare professionals **during** your cancer treatment?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  I did not need / want emotional or psychological support
- 

**Q46** **During** your cancer treatment, have you been given information or support from third sector organisations, such as charities or voluntary / community groups?

- 1  Yes and it was useful  
2  Yes, but it was not useful  
3  No  
4  I did not need help from the third sector  
5  Don't know / can't remember
- 

**Q47** Do you feel you have been supported emotionally and psychologically by third sector organisations **during** your cancer treatment?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  I did not need / want emotional or psychological support
- 

**Q48** Once your cancer treatment **finished** were you given information or support from third sector organisations?

- 1  Yes and it was useful  
2  Yes, but it was not useful  
3  No  
4  I did not need help from the third sector  
5  I am still having treatment  
6  Don't know / can't remember
- 

**Q49** If there is anything else you would like to tell us about any of the support you received during your cancer care, including from your GP Practice and third sector organisations, please do so here.

## 8. Your Overall Experience

**Q50** A care plan is a document received after diagnosis which sets out your needs and goals for caring for your cancer. This may include what treatment has been planned for you and the emotional, practical and financial support you will receive. It is an agreed plan between you and your health or social care professionals.

Have you been given a care plan?

- 1  Yes                      3  I do not know / understand what a care plan is  
2  No                         4  Don't know / can't remember
- 

**Q51** Have you been given a written note of the treatments you have received to treat your cancer?

- 1  Yes, for all of my treatments                      3  No  
2  Yes, for some of my treatments                      4  Don't know / can't remember
- 

**Q52** Overall, how easy did you find it to **travel to** appointments relating to your cancer care?

- 1  Very easy                      3  Neither easy or difficult                      5  Very difficult  
2  Quite easy                      4  Quite difficult
- 

**Q53** Which of the following difficulties did you experience when travelling to appointments relating to your cancer care? *Please tick all that apply.*

- 1  Length of travel time                      4  Cost of travel / parking                      7  Lack of information  
2  Frequency of travel                      5  Cost of accommodation                      8  Another difficulty  
3  Too unwell to travel                      6  Access to suitable transport                      9  I had no difficulties
- 

**Q54** Were you able to bring a family member, friend or someone else to your appointments to support you **when you wanted to**?

- 1  Yes, all of the time                      4  No because of difficulties with travel or cost  
2  Yes, most of the time                      5  No, for another reason  
3  Yes, some of the time                      6  I did not need / want to bring someone with me
- 

**Q55** Overall, how would you rate the **communication** around how long appointments relating to your cancer care would take?

- 1  Very good                      3  Neither good nor bad                      5  Very bad  
2  Good                      4  Quite bad                      6  Don't know / can't remember
- 

**Q56** Overall, do you feel that you have been treated with dignity and respect by the healthcare professionals treating you for cancer?

- 1  Yes, always                      2  Yes, most of the time                      3  Yes, sometimes                      4  No

**Q57** Overall, how would you rate the administration of your care, for example getting letters at the right time, doctors having the right notes / test results, etc.?

- 1  Very good      3  Neither good nor bad      5  Very bad  
2  Good      4  Quite bad      6  Don't know / can't remember
- 

**Q58** Did the different people treating and caring for you - such as your GP Practice, hospital staff, specialist nurses, community nurses - work well together to give you the best possible care?

- 1  Yes, always      4  No, never  
2  Yes, most of the time      5  Don't know / can't remember  
3  Yes, some of the time
- 

**Q59** Overall, how would you rate your care? *Please circle one number.*

Very poor      0   1   2   3   4   5   6   7   8   9   10      Very good

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**Q60** Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?

- 1  Yes      3  No but I would have liked them to  
2  No      4  Don't know / can't remember
- 

**Q61** If there is anything else you would like to say about your experiences of cancer care, please do so here.

## 9. About You

This information will help us to find out if different groups of people in Scotland have different experiences of health care services. Nobody involved in your health or care, including those at the hospital you attended, will be able to see your answers. If you would **prefer not to answer a particular question** then you can **leave it blank**.

**Q62** What best describes your gender?

- 1  Male      2  Female      3  Other

**Q63** Which of the following options best describes how you think of yourself?

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

**Q64** What best describes your ethnic group?

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

**Q65** What best describes your work status?

- 1  Employed (full or part time)      5  Don't work due to cancer  
2  Self-employed (full or part time)      6  Don't work due to another illness or disability  
3  In full-time education or training      7  Retired  
4  Unemployed/looking for work      8  Other

**Q66** Do you have any of the following? *Please tick **all that apply**.*

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

**Thank you for completing this survey.**

Please return the survey in the **freepost** envelope provided **as soon as possible**.  
Alternatively, you can **post it without a stamp to:**

[RETURN ADDRESS]