





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 **Autumn 2024**. 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/cpes**

Please use blue or black ink and don't worry if you make a mistake, simply cross it out and tick the correct answer. There is space at the end that you can use to tell us anything else you think we should know.



Helpline 0800 783 1775 Monday to Friday

For more information about this survey, please read the enclosed letter or visit www.gov.scot/cpes

1 L thought was necessary

1. Getting diagnosed	
	où first thought something might be wrong with you until professional or your General Practice?
Less than 3 months	More than 12 months
2 3 to 6 months	5 Don't know / can't remember
₃ 6 to 12 months	
see a healthcare professional at	ed to go to hospital about cancer, how many times did you t your General Practice about the health problem caused by hone, video and face to face consultations in your answer.
$_1$ Once \rightarrow Go to Q3	$_4$ 5 or more times \rightarrow Go to Q3
$_2$ Twice \rightarrow Go to Q3	I did not talk to anyone at my GP Practice → Go to Q4
$_3$ 3 or 4 times \rightarrow Go to Q3	₆ Don't know / can't remember → Go to Q3
	h of time you had to wait before your first professional at the hospital?
☐ I was seen as soon as I	☐ I should have been ☐ I should have been

² Lu seen a bit sooner

₃ L seen a lot sooner

Q4	endo	k about the first time you had a diagnosscopy, biopsy, mammogram or scan. Information you needed about your test	Knowing what you know now, did you have all
	1	Yes	No, I would have liked more written and verbal information
	2	No, I would have liked more written information	₅ I did not need / want any information
	3	No, I would have liked more verbal information	Don't know / can't remember
Q5	Were	e the results of your first diagnostic tes	t explained in a way you could understand?
	1	Yes, completely	I did not have an explanation, but I would have liked one
	2	Yes, to some extent	I did not need an explanation
	3	No, I did not understand the explanation	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.	Findi	ng out you had cancer	40
Q7		en you were first told that you had can g a family member or friend with you?	cer, were you told in advance that you could Please tick all that apply.
	1	Yes 3 It was not necessary	Don't know / can't remember
	2	No 4 I was told by video-caphone or letter	Hospital restrictions prevented me from taking someone with me
- Q8	How	v do you feel about the way you were to	old you had cancer?
	₁	It was done sensitively	It should have been done a lot more sensitively
	2	It should have been done a bit more sensitively	Thore sensitively
- Q9	Did	you understand the explanation of wha	at was wrong with you?
	1	Yes, I completely understood	No, I did not understand it
2		Yes, runderstood some of it	Don't know / can't remember
Q1	ca	ncer you had? Written information cou	re you given written information about the type of ld include printed information handed to you or were directed towards by your clinical team.
1		Yes and it was easy to understand	I did not need / want written information
2		Yes, but it was difficult to understand	d 5 Don't know / can't remember
3		No, I was not given written information about the type of cancer I had	n

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3. Deciding the best treatment for you

Individual treatment plans should be based on individual risk assessment, choice and expected outcome. When any of these factors change, the best treatment for you may also change, but this should always be discussed before decisions are made.

Q11	Befo	ore your treatment started	d, were yo	our treatme	nt opt	ions explained to yo	ou?
1		Yes, completely		3		No	X
2		Yes, to some extent		4		Don't know / can't	remember
Q12		e you involved in discuss ment options for you? T					
1		Yes, completely		4		I did not want to dis	scuss this
2		Yes, to some extent		5		Don't know / can't ı	remember
3		No, but I would have lik	ed to disc	cuss this			
Q13		e the possible side effecterstand?	s of treat	ment(s) exp	laine	d in a way you coul	d
1		Yes, definitely	NRK	3	No, I	out I would have like	ed an explanation
2		Yes, to some extent	74	4	Don'	t know / can't reme	mber
Q14		e you offered practical a treatment(s)?	dvice and	l support in	dealir	ng with the side effe	ects of
1		Yes, definitely	3	No, I was	not o	ffered any practical	advice or support
2		Yes, to some extent	4	Don't know	и / са	n't remember	
Q15		ore you started your treat tment that could affect yo					fects of the
1		Yes, definitely	3	No, but I v	vould	have liked an expla	nation
2		Yes, to some extent	4	Don't know	и / са	n't remember	
4. O	pera	tions, Radiotherapy	and Cl	hemother	ару		
Q16	Hav	e you had an operation,	such as r	emoval of a	tumo	our or lump, for you	r cancer?
1		$Yes \rightarrow \textbf{Go to Q17}$	2	$No o \mathbf{Go}$	to Q	21	

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Q1	7	Knov	about the last time you went into hospital for an operation for your cancer. ring what you know now, did you have all the information you needed about your tion 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
- Q1	8		the operation, did a member of staff explain how it had gone in a way you could stand?
	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
Q1	9		you given clear written information about what you should or should not do
		anter	he operation? Yes No Don't know / can't remember
-	1		2 No 3 Don't know / can't former inscri
Q2	20	Did	he operation take place at the hospital named on the survey letter?
	1		Yes ₂ Don't know / can't remember
Q2	21	Hav	e you had radiotherapy treatment?
	1		Yes, at the hospital named on the survey letter → Go to Q22
	2		Yes, at a different hospital to the one named on the survey letter → Go to Q22
	3		No — Go to Q23
Q2	22		ving what you know now, did you have all the information you needed about your therapy treatment beforehand?
	1		Yes, completely 2 Yes, to some extent 3 No
Q2	23	Have	you had chemotherapy treatment?
	1		Yes, at the hospital named on the survey letter \rightarrow Go to Q24
	2		Yes, at a different location to the one named on the survey letter → Go to Q24
	3		No → Go to Q25
Q2	4		ing what you know now, did you have all the information you needed about your otherapy treatment beforehand?
	1		Yes, completely 2 Yes, to some extent 3 No
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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.

Q25 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	2	3	4	5
They listened to me if I had any questions or concerns	1	2	3	4	5
They discussed my condition and treatment with me in a way I could understand	1	2	3 🔯	4	5
They gave me the opportunity to involve the people that matter to me	1	2	3	4	5
They helped me to feel in control of my treatment / care	1	2	3	4	5
They did not talk in front of me as if I wasn't there	1 CR	2	3	4	5
Q27 Did this experience take place at the pl	es, sometimene hospital i	es ₃ anamed on	No the survey lo	etter? ow / can't re	
Did a healthcare professional tell y condition or treatment? Yes and I was able to reach when I tried to make contact Yes, but I could not reach the when I tried to make contact	them 3 4 C	No, k	out I would hat out I did not r	ave liked the	em to
Q29 A Clinical Nurse Specialist is a spe and gives you help and advice on a Were you given the name of a Clin would support you through your tre	coping with ical Nurse \$	cancer.			
Yes, Clinical Nurse Specialis → Go to Q30	st	3	No o Go	to Q32	
Yes, named contact → Go to Q30		4	Don't kno → Go to	w / can't rer Q32	nember

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Q30 How easy or difficult has it be contact?	een for you to conta	ct your Clinica	al Nurse Spec	ialist or named			
₁ Very easy	4	Quite difficu	It				
2 Quite easy	5	Very difficul	t				
Neither easy nor difficu	It 6		to contact my ialist or name				
Q31 When you have had importar contact, how often did you ge			•	st, or named			
All or most of the time	3	Rarely or ne	ver				
2 Some of the time	4	I have not a	sked any que	stions			
6. Wider Support							
Q32 During your cancer treatment, were you given enough care and support from health or social services, for any of the following issues: Please tick one box on each line. If a statement is not applicable, please leave that line blank.							
	Yes, definitely	Yes, to some extent	No	I did not need help with this			
Mobility	1	2	3	4			
Washing / Dressing	ARE I	2	3	4			
Usual activities (work, study, housework, shopping, cooking, family or leisure activities)	1	2	3	4			
Eating	1	2	3	4			
Managing medications	1	2	3	4			
Pain / Discomfort	1	2	3	4			
Mental or emotional wellbeing	1	2	3	4			
Q33 Thinking about the last time treatment, did healthcare profinformation they needed to he	essionals give your	family, or sor					
Yes, definitely	4 This doe	s not apply to	me				
Yes, to some extent	My family / supporter(s) did not want to talk to a healthcare professional						
₃ No	6 Don't kno	ow / can't rem	nember				

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Q34 After your cancer treatment, were you given enough care and support from health or social services, for any of the following issues:

Please tick one box on each line. If a statement is not applicable, please leave that line blank.

	Yes, definitely	Yes, to some extent	No	I did not need help with this
Mobility	1	2	3	4
Washing / Dressing	1	2	3	4
Usual activities (work, study, housework, shopping, cooking, family or leisure activities)	1	2	3	
Eating	1	2	3	R 4
Managing medications	1	2	3 60	4
Pain / Discomfort	1	2	OD.	4
Mental or emotional wellbeing	1	2 0	3	4
7. Information and Other Suppor	rt	SK		
Q35 Did healthcare professionals disci			rmation abo	out the
1 Yes	di	4 It was	not necessa	ary
Yes, but I would have liked	it earlier	5 Don't k	now / can't	remember
₃ No, but I would have liked t	his			
Q36 Looking back, did you fully unde and / or its treatment on your day			oout the imp	pact of cancer
1 Yes 2 No	1	3 Don't kr	now / can't r	emember
Q37 Did healthcare professionals give benefits you might be entitled to?		ation about how	to get finan	cial help or any
1 Yes		₃ I did no	t need this	
No, but I would have liked t	his	Don't kr	now / can't r	emember
Q38 During your cancer treatment, we voluntary or community groups the		-	tion about o	charity,
1 Yes, it was useful		4 No		
2 Yes, but it was not useful		₅ I did no	ot need this	
3 Yes, but I would have liked	it earlier	6 Don't k	now / can't	remember
Q39 Do you feel you were supported production voluntary or community groups d				y by charity,
1 Yes, completely		₃ No		
2 Yes, to some extent		4 I did no	ot need / wa	nt support
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Q40		e your cancer treatment ommunity groups that co			n information about	charity, voluntary
1		Yes, it was useful		4	No	
2		Yes, but it was not use	ful	5	I did not need this	
3		Yes, but I would have	iked it earlier	6	Don't know / can't	remember
Q41	-	ou feel you were suppointary or community grou	•	•		ly by charity,
1		Yes, completely		3	No	
2		Yes, to some extent		4	I did not need / w	ant support
8. Yo	our C	Verall Experience				
Q42		rall, do you feel that you essionals treating you fo		eated with o	lignity and respect	by the healthcare
,		Yes, always ₂ Ye	s, most of the	e time 3	Yes, sometimes	No No
Q43	This and social	re plan is a document re may include what treatn financial support you wil al care professionals.	nent has bee I receive. It is	n planned fo an agreed	or you and the emo	tional, practical
	пач	e you been offered a wri Yes			understand what	a care nlan is
1			° 🗀	Q ~		a care plants
	· L	No	4 📖	DONTARIOW	/ can't remember	
Q44	Have can	e you been given a writte cer?	en note of the	treatments	you have received	to treat your
1		Yes, for all of my treatn	nents	3	No	
2		Yes, for some of my tre	atments	4	Don't know / can't	remember
Q45	Ove	rall, how easy did you fi	nd it to travel	to appointn	nents relating to yo	ur cancer care?
1		Very easy		4	Quite difficult	
2		Quite easy		5	Very difficult	
3		Neither easy or difficult				
Q46		ch of the following difficuing to your cancer care?				appointments
1		Length of travel time 5	Access transpor	to suitable t	8	Lack of information
2		Frequency of travel		f appointme o travel (trar		Another difficulty
3		Too unwell to 6 L travel		o traver (trai ole / rush ho		I had no difficulties
4		Cost of travel / parking 7	Cost of a	ccommodat	ion	
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Q47 How far did you have to travel for each of the following, and how did you travel? *Please tick all that apply and leave those that do not apply blank*.

tick all that apply and leave those that do not apply blank.								
	<u>Distance Travelled</u>				<u>Mo</u>	de of Tra	<u>avel</u>	
	Less than 10 miles	10 - 50 miles	More than 50 miles	Car	Bus / Train	Plane / Ferry	On foot / Bike	Other
Diagnostic tests (not including blood tests)	1	2	3	1	2	3	4	5
Blood tests	1	2	3	1	2	3	4	5
Chemotherapy	1	2	3	1	2	3	4	5
Radiotherapy	1	2	3	1	2	3	4	5
Surgery	1	2	3	1	2	3	4	5
Consultations with a healthcare professional	1	2	3	1	2	3	4	5
Support services (emotional / practical support)	1 .	2	з 🔲	1	2	3	4	5
Q48 Were you able to I support you when	_	•		nd or sor	meone els	e to your	appointm	ents to
1 Yes, all of the	e time → 0	Go to Q	50	4	No, social prevented		•	
2 Yes, most of	the time -	→ Go to	Q49		No, for an anything e			
3 Yes, some of	the time	→ Go t	6 Q49	6	I did not n someone		•	•
When you were not able to bring someone with you to an appointment or test, were alternative arrangements made so they could support you (e.g., were they able to join by phone or video call, or was a written summary of the discussion provided)?								
1 Yes	S 2 [No		3 🔲 🗆	Oon't know	/ can't re	emember	
Q50 How did the health and care team communicate with you at each stage? Please tick all that apply for each stage.								
NR LY		Face face	Tele	phone	Video call	Writing _a	Not applicable	Can't rememb

Please tick all that apply for each stage.						
MR L.Y	Face to face	Telephone	Video call	Writing	Not applicable	Can't remember
Initial contact from the hospital	1	2	3	4	5	6
Any appointment with a healthcare professional during your treatment	1	2	3	4	5	6
Receiving test results	1	2	3	4	5	6
Any appointment with a healthcare professional during your follow-up care	1	2	3	4	5	6
When discussing next steps	1	2	3	4	5	6

Q51 What would have been your preferred method of communication for each of these stages? Please tick all that apply for each stage.

	Face to face	Telephone	Video call	Writing	Not applicable	Can't remembe
Initial contact from the hospital	1	2	3	4	5	6
Any appointment with a healthcare professional during your treatment	1	2	3	4	5	6
Receiving test results	1	2	3	4	CS TO	6
Any appointment with a healthcare professional during your follow-up care	1	2	3	10	5	6
When discussing next steps	1	2	3	4	5	6
Q52 Overall, how would you rate letters at the right time, doct Very good	ors having				.?	
Good 4	Bad	RE	6	-	now / can't r	emember
Q53 Did the different people trea hospital staff, specialist nurs best possible care?						the
1 Yes, always	4	No, n	ever			
Yes, most of the time	5	Don't	know / ca	an't remei	mber	
yes, some of the time						
Q54 Since your diagnosis, has a research opportunities that donation, additional scans,	you could t	ake part in (fo				
1 Yes		3	No, but	l didn't wa	ant them to	
2 No, but I would have I	iked them	to 4	Don't kn	ow / can'	t remember	
Q55 Overall, how would you rate Very poor 0 1 2		Please circl 5 6	e one nu		ween 0 and	
9 Other Comments					,	

If there is anything else you would like to say about any aspect of your experiences of cancer care in Scotland, please do so on the following page.

Please note that the comments you write in the following boxes may be analysed by the Scottish Government, NHS Scotland, Local Health Boards, Macmillan and researchers analysing the data. Any information that could identify you will be removed before publishing the results of the analysis.

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What	was particularly good about your	care?	
What	could have been improved?		
			DONOTCOMPLETE
Any c	other comments?		~~
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		4 Ro	
10. Abou	t You 🤇		
different e including	mation will help us to find out if dif experiences of health care service those at the hospital you attended of to answer a particular question	s. Nobody I, will be ab	involved in your health or care, ble to see your answers. If you would
Q57 Whic	ch of the following best describes y	our sexua	orientation? Please tick one box only.
1	Straight / Heterosexual	4	Other sexual orientation
2	Gay or Lesbian	5	Prefer not to say
3	Bisexual		
Q58 Wha	it is your ethnic group?		
S	White (including Gypsy,		African, Scottish African
1	Traveller, Roma, Showman / Showwoman)	4	or British African (including any African ethnic group)
2	Mixed or multiple ethnic groups (including any mixed or multiple ethnic groups)	5	Caribbean or Black (including Scottish Caribbean, Black Scottish)
з 🔲	Asian, Asian Scottish or Asian British (including any Asian ethnic group)	6	Other ethnic group (any other ethnic group including Arab, Sikh, Jewish)
		7	Prefer not to say

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Q59	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
Q60	-	ou have any physical or mental health conditions or illnesses lasting or expected st 12 months or more?
4		Yes → Go to Q61
1 —		
Q61		ny of these conditions or illnesses affect you in any of the following areas? se tick all that apply.
1		Vision (for example, blindness or partial sight)
2		Hearing (for example, deafness or partial hearing)
3		Mobility (for example, walking short distances or climbing stairs)
4		Dexterity (for example, lifting or carrying objects, or using a keyboard)
5		Learning or understanding, or concentrating
6		Memory
7		Mental health
8		Stamina or breathing, or fatigue
9		Socially or behaviourally (for example, associated with autism spectrum disorder (ASD) which includes Asperger's, or attention deficit hyperactivity disorder (ADHD))
10		Other
11		Prefer not to say
Q62 Does your condition or illness / do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?		
1		Yes, a lot 3 Not at all
2		Yes, a little Prefer not to say
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 :		
		Freepost QUALITY HEALTH

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