



Scottish Cancer Patient Experience Survey 2018

Technical Report

Health and Social Care Analysis Division

April 2019



Contents

1. Introduction and Background	1
2. Survey Development	2
3. Sample Design	9
Access to Individuals' Names & Addresses	10
4. Fieldwork	11
Mail-outs	11
Survey Helpline Calls	11
People who were recently deceased	12
5. Data Entry and Fieldwork Quality Control	13
Data Capture	13
Verification and Upload Process	13
Secure Disposal	13
Free Text Comments	13
6. Survey Response	14
Overview	14
Response Rate by Age Group	14
Response Rate by Sex	15
Response Rates for NHS Boards	15
Response Rate by Deprivation	16
Response Rate by Urban / Rural Location	16
Response Rates by Tumour Group	17
Method of Response	17
7. Analysis and Reporting	18
Reporting the Age of Respondents	18
Reporting the Sex and Gender of Respondents	18
Number of Responses Analysed	18
Weighting	19
Backdating of Previous Surveys	19
Percentage Positive and Negative	19
Quality Assurance of the National Report	20
Revisions to previous publications	20
8. Outputs from the Survey	21
Interactive Dashboard	21
Supporting Data	21
Annex A: Per cent Positive and Negative Responses	22

1. Introduction and Background

This report provides information on the technical aspects of the 2018 Scottish Cancer Patient Experience Survey (SCPES), including development, implementation, analysis and reporting.

SCPES is one of a suite of national surveys which are part of the Scottish Care Experience Survey Programme. The surveys aim to provide local and national information on the quality of health and care services from the perspective of those using them. They allow local health and care providers to compare with other areas of Scotland and to track progress in improving the experiences of people using their services. Information about the other national care experience surveys is available at www.gov.scot/Topics/Statistics/Browse/Health/careexperience.

The survey programme supports the three quality ambitions of the *2020 Vision*¹ - Safe, Effective, Person-centred - by providing a basis for the measurement of quality as experienced by service users across Scotland. In particular the surveys support the person-centred quality ambition which is focused on ensuring that care is responsive to people's individual preferences, needs and values.

SCPES asks people across Scotland about their experience of cancer care. The survey is jointly funded by the Scottish Government and Macmillan Cancer Support, and is run in partnership with Information Services Division (ISD), part of NHS National Services Scotland. An approved survey contractor, Quality Health Ltd, was appointed to administer the survey fieldwork. This is the second iteration of SCPES, with the first iteration run in 2015 and results published in June 2016.

National results, as well as local level results by Regional Cancer Network, NHS Board and Cancer Centre, were published on 30 April 2019.

¹ www.gov.scot/Topics/Health/Policy/2020-Vision

2. Survey Development

The survey questionnaire for the 2015 SCPES was largely based on the Cancer Patient Experience Survey run in England. The content of the questionnaire was reviewed and updated ahead of the 2018 survey to ensure continued relevance of survey questions and to incorporate wider changes to health policy, such as the introduction of questions around person-centred behaviours. Details of the changes made to the questionnaire are detailed in Tables 1 to 3.

The survey materials were also revised ahead of the 2018 survey to improve engagement with respondents and to ensure compliance with General Data Protection Regulations in line with changes made to other surveys in the programme. This included improving the information provided to survey recipients in the covering letter and also introducing a privacy notice for the survey. The survey packs consisted of the following:

- **Initial Mailout:** A survey letter, a paper questionnaire, a freepost return envelope and an information leaflet including details of the survey helpline in a range of languages.
- **First Reminder:** A survey letter and an information leaflet including details of the survey helpline in a range of languages.
- **Second Reminder:** A survey letter, a paper questionnaire, a freepost return envelope and an information leaflet including details of the survey helpline in a range of languages.

Copies of all of the survey materials, including the privacy notice, can be found at www.gov.scot/CancerSurvey.

Table 1: New questions for the 2018 survey

Quest. No.	Topic	Question Text	Reason
13	Deciding treatment	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.	To gather data on experiences of person-centred care behaviours ² .
22	Operations, Radio and Chemo	Were you given clear written information about what you should or should not do after the operation?	Replaced 2015 Q39 as it was felt that it was more relevant following an operation than after hospital treatment which may be a regular appointment.
29a	Hospital care	They spent enough time with me	To gather data on experiences of person-centred care behaviours ² . Consistent with questions used in other Patient Experience surveys.
29b	Hospital care	They listened to me if I had any questions or concerns	To gather data on experiences of person-centred care behaviours ² . Consistent with questions used in other Patient Experience surveys.
29c	Hospital care	They discussed my condition and treatment with me in a way I could understand	To gather data on experiences of person-centred care behaviours ² . Consistent with questions used in other Patient Experience surveys.
29d	Hospital care	They gave me the opportunity to involve the people that matter to me	To gather data on experiences of person-centred care behaviours ² . Consistent with questions used in other Patient Experience surveys.
29e	Hospital care	They helped me to feel in control of my treatment / care	To gather data on experiences of person-centred care behaviours ² . Consistent with questions used in other Patient Experience surveys.
45	Other support	Do you feel you have been supported emotionally and psychologically by healthcare professionals during your cancer treatment?	To gauge level of emotional / psychological support provided by healthcare professionals during cancer treatment.

² www.healthcareimprovementscotland.org/our_work/person-centred_care/person-centred_programme.aspx

Quest. No.	Topic	Question Text	Reason
46	Other support	During your cancer treatment, have you been given information or support from third sector organisations, such as charities or voluntary / community groups?	To understand level of information / support provision by third sector during cancer treatment and to assess if it has been useful.
47	Other support	Do you feel you have been supported emotionally and psychologically by third sector organisations during your cancer treatment?	To gauge level of emotional / psychological support provided by third sector during cancer treatment.
48	Other support	Once your cancer treatment finished were you given information or support from third sector organisations?	To understand level of information / support provision by third sector after cancer treatment and to assess if it has been useful.
51	Overall experience	Have you been given a written note of the treatments you have received to treat your cancer?	To gauge prevalence of treatment summaries.
52	Overall experience	Overall, how easy did you find it to travel to appointments relating to your cancer care?	To understand prevalence of difficulty with travelling to appointments and how this is dispersed across respondent groups.
53	Overall experience	Which of the following difficulties did you experience when travelling to appointments relating to your cancer care? Please tick all that apply.	To understand what difficulties relating to travel are most common and how these are dispersed across the country.
54	Overall experience	Were you able to bring a family member, friend or someone else to your appointments to support you when you wanted to?	To understand whether difficulties with travel impact on people's ability to bring someone for support.
55	Overall experience	Overall, how would you rate the communication around how long appointments relating to your cancer care would take?	Replaced 2015 Q62 to get more useable data on communication of length of appointments.
56	Overall experience	Overall, do you feel that you have been treated with dignity and respect by the healthcare professionals treating you for cancer?	Replaced 2015 Q38 to reflect that individuals should be treated with dignity and respect throughout their cancer care, not just in hospital.

Table 2: Questions that were changed in the 2018 survey

2015 Q. No.	2018 Q. No.	Topic	Question Text	Reason
1	1	Getting diagnosed	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?	Routing has been introduced to ensure those who went straight to hospital are not asked further questions about experiences of primary care diagnosis routes. Data on screened diagnosis routes can be linked to from SMR06.
3	2	Getting diagnosed	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?	Will only be answered by those with a primary care diagnosis route. Question broadened to healthcare professional, rather than doctor specifically.
2	3	Getting diagnosed	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	Will only be answered by those with a primary care diagnosis route.
5	4	Getting diagnosed	Think about the first time you had a diagnostic test for cancer. Knowing what you know now, did you have all the information you needed about your test beforehand?	Focus changed to first diagnostic test, rather than last as felt that this improved question flow. Question text rephrased to emphasise reflective nature of question. Additional response option included and "tick all" instruction removed.
7	5	Getting diagnosed	Were the results of your first diagnostic test explained in a way you could understand?	Focus changed to first diagnostic test, rather than last as felt that this improved question flow.
25	20	Operations, Radio & Chemo	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?	Question text rephrased to emphasise reflective nature of question. Additional response option included and "tick all" instruction removed.

2015 Q. No.	2018 Q. No.	Topic	Question Text	Reason
46 & 49	24	Operations, Radio & Chemo	Have you had radiotherapy treatment?	Response options modified to allow two 2015 questions to be asked as one to save space.
50 & 53	26	Operations, Radio & Chemo	Have you had chemotherapy treatment?	Response options modified to allow two 2015 questions to be asked as one to save space.
-	-	Hospital care	Section as a whole	Amended to ask about last hospital experience with no distinction between inpatient and outpatient.
29	29f	Hospital care	They talked in front of me as if I wasn't there	Response options changed to allow question to be incorporated into tabular format. Broadened to healthcare professionals.
34	30	Hospital care	The last time you received hospital treatment for your cancer, did the healthcare professionals caring for you call you by your preferred name?	Focus of question changed to whether name was used as may be familiar with staff and so might not ask preferred name each time but should still use it. Broadened to healthcare professionals.
21 to 23	41 to 43	Other support	Questions on support and information provided by healthcare professionals	Broadened to healthcare professionals, was previously asked about hospital staff but some of this information may have come from other healthcare professionals, such as GP Practice.
54	44	Other support	Did healthcare professionals give your family or someone else close to you all the information they needed to help care for you at home?	Broadened to healthcare professionals and response options simplified to group all "not relevant to me" type responses into one.
60	50	Overall experience	Have you been given a care plan?	The explanation of care plan that is provided has been expanded to make it clearer for respondents.
69 to 73	62 to 66	About You	Demographic questions	Question and response options made consistent with other Scottish Patient Experience surveys.

Table 3: Questions that were removed for the 2018 survey

2015 Q. No.	Topic	Question Text	Reason
4	Getting diagnosed	Have you had a diagnostic test for cancer?	Not required – all respondents have a confirmed cancer diagnosis (as per SMR06) and so must have had a diagnostic test.
6	Getting diagnosed	Overall, how did you feel about the length of time you had to wait for your test to be done?	Data has limited use, removed in order to prioritise questions which focus on experience of person-centred behaviours throughout the cancer care journey.
28	Hospital care	Have you had an operation or stayed overnight for cancer care?	As inpatient and outpatient sections have now been grouped, this question is no longer required.
30 & 32	Hospital care	Did you have confidence and trust in the doctors / ward nurses treating you?	Positive experiences of person-centred behaviours are generally correlated to confidence and trust. Question has been removed in favour of questions on specific person-centred behaviours.
31	Hospital care	If your family or someone else close to you wanted to talk to a doctor, were they able to?	Limited accuracy of data as not a direct experience for the respondent, would be from a second-hand perspective.
33	Hospital care	In your opinion, were there enough nurses on duty to care for you in hospital?	Question has been removed in favour of questions on experience of care via specific person-centred behaviours, particularly Q29.
36 & 43	Hospital care	Did you find someone on the hospital staff to talk to about your worries and fears?	Replaced by Q29b
37	Hospital care	Do you think the hospital staff did everything they could to help control your pain?	Question has been removed in favour of questions on experience of care via specific person-centred behaviours. In particular, Q29b, c & e which should incorporate this.
38	Hospital care	Overall, did you feel you were treated with respect and dignity while you were in hospital?	Replaced by Q56 as should experience this throughout cancer journey, not just in hospital.
39	Hospital care	Were you given clear written information about what you should or should not do after leaving hospital?	Replaced by Q22 as more relevant post operations. Some respondents will be thinking of more regular hospital appointments where this may not apply.

2015 Q. No.	Topic	Question Text	Reason
42	Hospital care	Have you been treated as an outpatient or day case for cancer care?	As inpatient and outpatient sections have now been grouped, this question is no longer required.
44	Hospital care	The last time you had an outpatients appointment with a cancer doctor, did they have the right documents?	Individuals may not know. Removed in favour of questions on person-centred behaviours.
48 & 52	Radio & Chemo	Once you started your treatment, were you given enough information about whether your radiotherapy / chemotherapy was working in a way you could understand?	Removed as clinical advisors noted that it is unlikely information of this type would be provided due to the uncertain nature of the treatments and how they work.
57	Support from health & social services	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	Individuals may not know. Removed in favour of questions on person-centred behaviours.
62	Overall experience	Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	Data has limited use, removed in order to prioritise questions which focus on experience of person-centred behaviours throughout the cancer care journey.
65 to 67	About you	Questions on respondents cancer and how they are at time of responding.	Data on individuals' cancer can be linked to using SMR06 data. This will allow us to do any additional analysis required using stage or grade of cancer.
68	About you	What was your age on your last birthday?	Age of respondent now being taken from administrative records (see Section 8 for more information).
74 to 76	About you	Questions on permission to use contact details / link survey data in future.	These questions were removed as part of the information governance review of this survey. Information about how data will be used was provided to respondents in a privacy notice.

3. Sample Design

The sampling was carried out by ISD using IBM SPSS software version 24.0 and was designed to:

- provide results at national, Regional Cancer Network, NHS Board and Cancer Centre levels;
- provide feedback relating to recent experiences;
- include people who had experienced the range of cancer care services; and
- minimise the chances of sending the survey to individuals who did not have cancer or who had died since leaving hospital.

ISD used a national dataset containing records of acute hospital activity (SMR01) to identify people aged 16 or over with an inpatient or day case record with any mention of cancer and a discharge date between 1 January 2017 and 30 September 2017.

Where a person had more than one hospital record meeting the above criteria, the most recent hospital episode was selected. This ensured that each person only appeared in the sample once.

In order to confirm the diagnosis of cancer, and to minimise the risk of sending surveys to patients who did not have cancer, validation was completed using the Scottish Cancer Registry (SMR6). Individuals who were identified from the hospital records but did not have a confirmed Scottish Cancer Registry diagnosis date between 1 July 2016 and 31 March 2017 were excluded from the sample.

The following patients were also excluded from the sample:

- Patients who are known to be deceased.
- Privately funded patients receiving care in NHS or private hospitals.
- Patients treated in a private hospital / hospice.
- Scottish NHS patients treated in hospitals outside of Scotland but whose care was commissioned by an NHS Board.
- Patients who were not resident in Scotland.
- Patients who stayed in hospital for termination of pregnancy and / or conditions relating to pregnancy and childbirth.
- Patients who stayed in a hospital maternity unit.
- Patients who were resident in a long-stay hospital.
- Patients who were being treated for a mental health condition in a mental illness hospital.
- Patients who were being treated in a learning disabilities unit.
- Patients with an ICD10 code of C44 and all other C44 classifications (non-melanoma skin cancers).
- Patients with an ICD10 code of C84 and all other C84 classifications (rare haematological cancers with complex clinical definitions).
- Patients with an ICD10 code of D05 and all other D05 classifications (in situ breast cancers).

Addresses were obtained from the CHI database and checked to ensure that they were complete. Any records where the address was incomplete were removed from the sample.

To ensure a sufficiently large response to the survey, a census approach was taken. This means that surveys were sent to all qualifying patients, rather than just a restricted sample of them. A total of 8,302 people were sampled for inclusion in SCPES 2018.

This sampling approach was proposed following a small review and was agreed with the survey's Stakeholder Group. It is consistent with the sampling methodology used in the 2015 survey, with one additional exclusion – those with an ICD10 code of D05. This change has been made following feedback from the 2015 survey which showed that, due to the variation in clinical definition of these types of tumours, a high proportion of helpline calls regarding cancer diagnosis concerns were from individuals with this type of tumour. This could lead to distress / anxiety for these individuals and so it was agreed that this tumour type should be excluded from future surveys. Using the same sampling methodology between surveys ensures a consistent approach and allows for robust comparisons over time.

Access to Individuals' Names & Addresses

Approval was given by the Public Benefit and Privacy Panel (PBPP)³ to use NHS data to identify a survey sample and approach individuals. A copy of the approval letter is available at www2.gov.scot/Resource/0053/00537065.pdf.

Data transfers containing individuals' names and addresses were done securely and were limited to variables required to mail the survey pack to the individual and identify which hospital their sample record related to. All data was accessed, managed and stored in accordance with the data confidentiality protocols described in the privacy notice for the survey⁴.

³ www.informationgovernance.scot.nhs.uk/pbpphsc/

⁴ www2.gov.scot/Topics/Statistics/Browse/Health/cancersurvey/SCPESPrivacyNotice

4. Fieldwork

The Scottish Government contracted Quality Health Ltd to administer the survey. Quality Health Ltd has in-depth experience of NHS surveys, and has provided support for other care experience survey work both in Scotland and elsewhere in the UK. ISD provided support for the administration of the survey.

Respondents had the option to complete the survey by post, online, via a telephone helpline in a wide range of languages or via text phone. The helpline was also available to handle questions or complaints about the survey.

Mail-outs

The fieldwork began on 19 September 2018 with the mailout of the initial survey packs. A first reminder was sent to those who had not responded to the initial survey pack on 10 October 2018, and a second reminder was sent to those who had still not responded on 7 November 2018. The survey closed on 19 December 2018.

Survey Helpline Calls

During the fieldwork, the survey helpline received a total of 291 calls. The most common reason for calling the helpline was individuals advising that they did not want to complete the survey or receive any further survey letters (Table 4).

A small number of those sampled (0.3 per cent) contacted the survey helpline to query their eligibility for the survey. Of those that contacted the helpline to query their eligibility, seven individuals wanted their call escalated, that is they wanted a follow-up call from their NHS Board regarding their query. The remaining 20 individuals did not wish to escalate their call, that is they did not wish to pursue the matter any further. Details for all individuals who called regarding their eligibility in relation to their cancer diagnosis were double-checked against the Scottish Cancer Registry.

Table 4: Number of calls to the survey helpline, by main reason for the call

Main reason for call	2015	2018
To opt out of the survey	164	164
To complete the survey by phone	17	53
General query	39	42
To query eligibility – not escalated	31	18
To query eligibility – escalated	12	7
To advise respondent deceased	7	4
Complaint	0	3
Total	270	291

The number of calls to the helpline by main reason for call is broadly consistent with those from 2015. Most notably:

- there were more telephone completions in 2018 – this is likely due to the changes to the mailout methodology that were implemented for the 2018 survey; and
- there were fewer calls to query eligibility in 2018 – this may be related to the exclusion of ‘breast in situ’ tumours from the 2018 sample as this group made up a large proportion of these calls for the 2015 survey.

People who were recently deceased

Individuals included in the 2018 survey were sampled on 1 August 2018. The sampling, questionnaire printing and mail-out process extended from this date through to the final mailing date of 7 November 2018. This meant that some people would have died between the extract date and mail out dates. As with all Care Experience surveys, every possible effort was made to avoid questionnaires being sent to family members of people who had died.

A list of people included in the initial sample was checked against the National Records of Scotland death register to identify people who had recently died so they could be removed from the sample. The list of people sampled for the survey was also shared with Atos Origin Alliance (who host the CHI database) and the NHS Central Register (NHS CR). This allowed Atos and NHS CR to check for people who had died and send notifications to ISD throughout the mail-out period. ISD subsequently passed this information on to Quality Health Ltd, who removed survey packs as required prior to each mailout.

Having access to information about recent deaths greatly reduced the number of questionnaires being sent to addresses of people who had died. Between the CHI and NHS CR databases, a total of 152 records included in the initial sample were flagged as deceased between the time the sample was finalised and the final mail out. All of these deceased records were removed prior to mailing questionnaires to people. We are grateful to NHS CR and Atos Origin Alliance for their help and support during this stage of the project.

Any death which occurs in Scotland must be registered within eight days of the date of death. This means that there can be a delay between the actual date of death and the date that it is registered and updated on the CHI and NHS CR databases. This delay can mean it is extremely difficult to prevent any questionnaires being sent to addresses of people who have died. In four cases a questionnaire was sent to someone who had died shortly after the death checks had been made and the person’s family contacted Quality Health Ltd to notify them of this. However, as outlined above, efforts were made to avoid this as much as possible.

5. Data Entry and Fieldwork Quality Control

Data Capture

Online responses were captured automatically and telephone completions were captured by the helpline team. Paper responses were logged and scanned on a daily basis by staff at Quality Health Ltd. A verification process was then carried out for each batch scanned and a number of integrity checks were undertaken to ensure the scanning process had worked correctly and all data had been captured as expected.

Data from online questionnaires and telephone completions are automatically stored alongside the data from the paper questionnaires, and held separately from the names and addresses of people who were sampled for the survey.

Verification and Upload Process

Once captured, all data are checked in house by Quality Health Ltd according to pre-set verification rules, by staff who have been given training and detailed instructions about the survey. The data entry system ensured that only valid answer codes for each question could be entered and that the correct data appeared in each field. Other checks included ensuring that numeric data was in the correct format and that fields were not truncated in error.

Once the survey responses were transferred to ISD and Scottish Government statisticians, further validation checks were run on the data to ensure data integrity was maintained.

Secure Disposal

The names and addresses of people who were selected for the survey were stored securely by Quality Health Ltd until the end of the fieldwork period. They were then destroyed.

Once processed, all returned questionnaires were immediately stored by Quality Health Ltd in labelled containers and archived in a secure room on-site until they reached their agreed destruction date. Once destroyed a certificate of destruction was provided.

Free Text Comments

The survey asked respondents if there was anything else that they would like to note about their experiences of the various aspects of their cancer care. Around 3,300 respondents left at least one comment. Analysis of these comments will be carried out and reported separately from the national results.

Disclosive details that could be used to identify people were suppressed when the comments were entered by staff at Quality Health Ltd. These details included personal names, addresses, medical conditions and dates. Staff names were also suppressed. Quality checks were undertaken on records to ensure that the instructions for suppressing disclosive details were followed.

6. Survey Response

Overview

The response rate for the survey is the number of forms returned as a percentage of the number of people in the sample once those considered ineligible have been removed. Ineligible people were those who had died between the sample being finalised and receiving any of the survey letters, had moved address or had informed the helpline they were ineligible for another reason.

There were two respondents who declined to participate in the survey and requested that their personal details be deleted by Quality Health Ltd. Whilst these individuals personal information was deleted by the survey contractor as per their request, they are still included in the population totals used in this survey as they were eligible to be sampled.

Of the 8,302 people in the final sample, 8,090 were considered eligible. A total of 5,001 surveys were returned completed, giving an **overall response rate of 62 per cent** – one percentage point higher than the response rate for 2015 (61 per cent).

This section describes the differences in response rates by a range of variables.

Response Rate by Age Group ⁵

The response rate increased with age, from 31 per cent for those aged between 16 and 34, to 71 per cent for those aged between 65 and 74 (Table 5). It then dropped back to 62 per cent for those in the oldest age group, 75 and above.

Table 5: Response rate by age group

Age Group	Number of eligible people sampled	Number of Responses	Response rate (%)
16 to 34	189	59	31
35 to 44	384	172	45
45 to 54	1,062	551	52
55 to 64	1,954	1,205	62
65 to 74	2,528	1,789	71
75 +	1,973	1,225	62
Scotland	8,090	5,001	62

⁵ Based on information held on the CHI database and calculated as age at date of sampling (1 August 2018).

Response Rate by Sex ⁶

As shown in Table 6, response rates for males and females were similar (63 and 61 per cent respectively).

Table 6: Response rate by sex

Gender	Number of eligible people sampled	Number of Responses	Response rate (%)
Male	3,646	2,285	63
Female	4,444	2,716	61
Scotland	8,090	5,001	62

Response Rates for NHS Boards

Looking at NHS Boards with more than 50 respondents, response rates by NHS Board of Treatment ranged from 55 per cent in NHS Lanarkshire to 70 per cent in NHS Highland (Table 7).

Table 7: Response rate by NHS Board of Treatment

NHS Board of Treatment	Number of eligible people sampled	Number of Responses	Response rate (%)
NHS Ayrshire & Arran	462	304	66
NHS Borders	124	84	68
NHS Dumfries & Galloway	117	79	68
NHS Fife	326	197	60
NHS Forth Valley	239	138	58
NHS Grampian	895	609	68
NHS Greater Glasgow & Clyde	2,626	1,537	59
NHS Highland	343	239	70
NHS Lanarkshire	568	310	55
NHS Lothian	1,567	985	63
NHS Orkney	*	*	60
NHS Shetland	*	*	70
NHS Tayside	615	390	63
NHS Western Isles	*	*	100
Golden Jubilee	161	97	60

Note: The number of forms sent out and the number of responses have been suppressed, "**", for NHS Boards with fewer than 50 respondents.

⁶ Based on information held on the CHI database

Response Rate by Deprivation

Respondents were assigned to a deprivation quintile based on their home postcode at the time of their treatment using the 2016 Scottish Index of Multiple Deprivation (SIMD)⁷. As in other Care Experience surveys, the response rate was lower for more deprived areas, ranging from 51 per cent for people living in the most deprived areas to 68 per cent for people living in the least deprived areas (Table 8).

Table 8: Response rate by deprivation quintile

SIMD Quintile	Number of eligible people sampled	Number of Responses	Response rate (%)
1 (Most deprived)	1,523	772	51
2	1,565	931	59
3	1,663	1,058	64
4	1,712	1,137	66
5 (Least deprived)	1,626	1,102	68
Scotland	8,090	5,001	62

Note: The Scotland figure includes one individual whose SIMD quintile is unknown and so the columns will not sum to the Scotland totals.

Response Rate by Urban / Rural Location

Respondents were assigned to an Urban / Rural category based on their home postcode at the time of their treatment using the 2013/14 Six-fold Urban / Rural classification⁸. The response rates ranged from 58 per cent for people living in large urban areas, to 71 per cent for people living in remote rural areas (Table 9).

Table 9: Response rate by urban / rural category

Urban / Rural Category	Number of eligible people sampled	Number of Responses	Response rate (%)
Large urban areas	2,624	1,517	58
Other urban areas	2,789	1,685	60
Accessible small towns	795	508	64
Remote small towns	278	181	65
Accessible rural	1,018	691	68
Remote rural	585	418	71
Scotland	8,090	5,001	62

Note: The Scotland figure includes one individual whose Urban / Rural category is unknown and so the columns will not sum to the Scotland totals.

⁷ www.gov.scot/Topics/Statistics/SIMD

⁸ www.gov.scot/Topics/Statistics/About/Methodology/UrbanRuralClassification

Response Rates by Tumour Group

Response rate by tumour group ranged from 44 per cent for those with another tumour type, to 67 per cent for those with prostate cancer (Table 10).

Table 10: Response rate by Tumour Group

NHS Board of Treatment	Number of eligible people sampled	Number of Responses	Response rate (%)
Breast	1,862	1,210	65
Colorectal / Lower Gastrointestinal	1,201	748	62
Gynaecological	698	418	60
Haematological	795	494	62
Head and Neck	511	301	59
Lung	574	326	57
Prostate	1,035	694	67
Skin	267	158	59
Upper Gastrointestinal	326	193	59
Urological	642	381	59
Other	179	78	44
Scotland	8,090	5,001	62

Note: The 'Other' category includes all tumour groups with fewer than 50 respondents (Brain / Central Nervous System, Sarcoma, Other) and respondents for whom a tumour group is not known.

Method of Response

Of the 5,001 respondents, 85 per cent sent their surveys back by post with almost all of the rest completing the survey online. Fifty-three people completed their survey via the telephone (Table 11). This pattern is broadly in line with that seen in the 2015 survey.

Table 11: Response by method

Method	Number of questionnaires completed	Questionnaires completed (%)
Online	675	13
Post	4,273	85
Telephone helpline	53	1
Language line	0	0
Scotland	5,001	100

7. Analysis and Reporting

The survey data collected and coded by Quality Health Ltd were securely transferred to ISD Scotland, where the information was analysed using the statistical software package IBM SPSS version 24.0.

Reporting the Age of Respondents

Respondent date of birth was taken from their CHI record at the time of data extraction. This source was used for all stages of the analysis. The age of respondents used for reporting purposes was calculated as at 1 August 2018.

Reporting the Sex and Gender of Respondents

Analysis of survey response rates by sex was undertaken using the sex of people in the sample according to their CHI record at the time of data extraction. This source was also used in the calculation of the survey weights (more information about this is provided later in this section).

All other analyses has been undertaken using gender, the respondents' answer to question 62 "What best describes your gender?". In total, 4,926 responders (99 per cent) provided a valid response to Q62.

Number of Responses Analysed

The number of responses that have been analysed for each question is often lower than the total number of survey responses received. This is because not all of the questionnaires that were returned could be included in the calculation of results for every individual question. In each case this was for one of the following reasons:

- The specific question did not apply to the respondent and so they did not answer it. For example, if they had not had an operation for their cancer and therefore did not answer questions about their experience of this.
- The respondent provided an answer indicating that a question did not apply to them. For example, if they did not need or want help from the third sector.
- The respondent did not answer the question for another reason (e.g. refused). People were advised that if they did not want to answer a specific question they should leave it blank.
- The respondent answered that they did not know or could not remember the answer to a particular question.
- Responses may be removed following validation checks, for example if a respondent selected an invalid combination of responses. Improved validation checks were introduced for this survey to ensure consistency between online and paper responses.

The number of responses that have been analysed nationally for each of the positive / negative questions are shown in Annex A.

Weighting

When conducting a survey, it is important to have a representative sample of the population you are interested in. Applying weighting methods reduces potential bias by making the results more representative of the population.

Survey weights are numbers associated with the responses that specify the influence the various observations should have in the analysis. The final survey weight associated with a particular response can be thought of as a measure of the number of population units represented by that response.

Results for the 2015 SCPEs were presented unweighted, however, weighting was introduced for the 2018 survey to take account of any non-response bias in the survey and ensure responses were representative of the sample population. A paper setting out the details of this review and the weighting methodology applied to the 2018 results is available at www2.gov.scot/Resource/0054/00542173.pdf.

Results at national, Regional Cancer Network and NHS Board levels have been weighted. Results at Cancer Centre level continue to be presented unweighted.

Backdating of Previous Surveys

Due to the methodological changes introduced for this survey, results from the 2015 survey have been backdated where appropriate to ensure comparisons over time are available. Reports specifically relating to the 2015 survey **will not** be updated to include the backdated figures.

As part of the backdating process, the improved validation checks brought in for the 2018 survey have been applied to the 2015 survey responses. This means the total number of responses analysed for some questions will differ from those previously published.

Percentage Positive and Negative

Per cent or percentage positive is frequently used in reporting results from this survey. This means the percentage of people who answered in a positive way. Annex A details which answers have been classed as positive, neutral and negative for each question.

Percentage positive is mainly used to allow easier comparison, particularly where responses are on a scale where there may be multiple responses being classed as positive or negative. There is also a belief that differences between answers on scales with five or more points may be subjective. For example there may be little or no difference between a person who “strongly agrees” and one who “agrees” with a statement. In fact some people may never strongly agree or strongly disagree with any statements.

As described in Section 4 of this report, these results are based on a sample of patients and are therefore affected by sampling error. The effect of this sampling error is relatively small for the national estimates. However, when comparisons have been made in the analysis of the survey results, the effects of sampling error have been taken into account by the use of confidence intervals and tests for statistical significance. Only differences that are statistically significant are reported as differences within the analysis and all significance testing is carried out at the 5% level.

More information on confidence intervals, significance testing and how they're calculated can be found at: www.gov.scot/Resource/0052/00522932.pdf.

Quality Assurance of the National Report

A restricted number of colleagues at Macmillan Cancer Support and ISD were sent a draft version of the national report for quality assurance purposes. Feedback received was taken into account when finalising the national report.

Revisions to previous publications

A copy of our revisions policy is available at: www.gov.scot/Resource/0052/00522934.pdf

8. Outputs from the Survey

This section provides details of the outputs from the 2018 SCPES that were published alongside the national report.

Interactive Dashboard

The local level results for the survey – Regional Cancer Network, NHS Board and Cancer Centre levels – are available via an interactive dashboard which can be accessed through a link on www.gov.scot/CancerSurvey.

The dashboard includes the following information:

- **Summary of Results:** Displays the five most positive and five most negative per cent positive questions for a selected area.
- **Per cent Positive Results:** Results for all the per cent positive style questions in the survey (as listed in Annex A) for a selected area. This also includes statistical comparisons to the Scotland figures and to 2015 results where appropriate. There is also the option to view the results for two different selected areas side by side.
- **Range of Per cent Positive Results:** Displays the results for per cent positive style questions for a selected area in relation to the overall range for the relevant level. For example, if an NHS Board of Treatment is selected, the range will be the range of per cent positive results across all NHS Boards of Treatment. The national result is also included.
- **Information Questions:** Results for all information questions, i.e. those questions that are not classed as per cent positive, for a selected area. There is also the option to view the results for two different selected areas side by side. No statistical comparisons have been carried out on these questions.
- **Response Rates & Demographics:** Displays the response rate and demographic information for a selected area.
- **Movement of Patients Receiving Cancer Care:** Shows the movement of survey respondents between NHS Board of Residence and NHS Board of Treatment.

More detailed notes on how to navigate and interpret the dashboards are provided within the dashboard itself.

Ahead of the 2018 survey, a review of how responses are allocated at local levels was undertaken. A paper summarising the review and the new approach applied to the 2018 results is available at www2.gov.scot/Resource/0054/00542172.pdf.

Supporting Data

Spreadsheets showing more detailed results are available on the Scottish Government website at www.gov.scot/CancerSurvey.

Annex A: Per cent Positive and Negative Responses

Table A1 shows how responses to per cent positive questions have been classed – each value relates to the response option as denoted in questionnaire – and how many respondents there were **nationally** for each question.

Table A1: Number of respondents and response codes for per cent positive style questions

Question Number	Topic	Question Text	Positive values	Neutral values	Negative values	Excluded values	Number of responses analysed
3	Getting diagnosed	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	1	2	3	-	3,752
4	Getting diagnosed	Think about the first time you had a diagnostic test for cancer. Knowing what you know now, did you have all the information you needed about your test beforehand?	1	-	2, 3, 4	5, 6	4,614
5	Getting diagnosed	Were the results of your first diagnostic test explained in a way you could understand?	1	2	3, 4	5, 6	4,864
7	Finding out about your cancer	When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	1	-	2	3, 4, 5	3,901
8	Finding out about your cancer	How do you feel about the way you were told you had cancer?	1	2	3	-	4,912
9	Finding out about your cancer	Did you understand the explanation of what was wrong with you?	1	2	3	4	4,922
10	Finding out about your cancer	When you were told you had cancer, were you given written information about the type of cancer you had?	1	-	2, 3	4, 5	4,122

Question Number	Topic	Question Text	Positive values	Neutral values	Negative values	Excluded values	Number of responses analysed
12	Deciding the best treatment	Before your treatment started, were your treatment options explained to you?	1	2	3	4, 5	4,196
13	Deciding the best treatment	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	2	3	4, 5	4,729
14	Deciding the best treatment	Were the possible side effects of treatment(s) explained in a way you could understand?	1	2	3	4, 5	4,569
15	Deciding the best treatment	Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	1	2	3	4	4,562
16	Deciding the best treatment	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	2	3	4, 5	4,134
17	Deciding the best treatment	Were you involved as much as you wanted to be in decisions about your care and treatment?	1	2	3	4	4,763
20	Operations, Radiotherapy, Chemotherapy	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	-	2, 3, 4	5	3,502
21	Operations, Radiotherapy, Chemotherapy	After the operation, did a member of staff explain how it had gone in a way you could understand?	1	2	3	4, 5	3,502

Question Number	Topic	Question Text	Positive values	Neutral values	Negative values	Excluded values	Number of responses analysed
22	Operations, Radiotherapy, Chemotherapy	Were you given clear written information about what you should or should not do after the operation?	1	-	2	3	3,208
25	Operations, Radiotherapy, Chemotherapy	Knowing what you know now, did you have all the information you needed about your radiotherapy treatment beforehand?	1	2	3	4	2,267
27	Operations, Radiotherapy, Chemotherapy	Knowing what you know now, did you have all the information you needed about your chemotherapy treatment beforehand?	1	2	3	4	2,232
29a	Hospital Care	They spent enough time with me	1, 2	3	4, 5	-	4,860
29b	Hospital Care	They listened to me if I had any questions or concerns	1, 2	3	4, 5	-	4,801
29c	Hospital Care	They discussed my condition and treatment with me in a way I could understand	1, 2	3	4, 5	-	4,821
29d	Hospital Care	They gave me the opportunity to involve the people that matter to me	1, 2	3	4, 5	-	4,674
29e	Hospital Care	They helped me to feel in control of my treatment / care	1, 2	3	4, 5	-	4,707
29f	Hospital Care	They talked in front of me as if I wasn't there	4, 5	3	1, 2	-	4,649
30	Hospital Care	The last time you received hospital treatment for your cancer, did the healthcare professionals caring for you call you by your preferred name?	1	2	3	-	4,870

Question Number	Topic	Question Text	Positive values	Neutral values	Negative values	Excluded values	Number of responses analysed
31	Hospital Care	Were you given enough privacy when discussing your condition or treatment?	1	2	3	-	4,895
32	Hospital Care	Did a healthcare professional tell you who to contact if you were worried about your condition or treatment after you left hospital?	1	-	2	3	4,711
36	Support from Health & Social Services	How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	1, 2	3	4, 5	6	3,365
37	Support from Health & Social Services	When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	1	2	3	4	3,236
38	Support from Health & Social Services	Do you think your GP Practice did everything they could to support you while you were having cancer treatment?	1	2	3	4	3,521
39	Support from Health & Social Services	During your cancer treatment, have you been given enough care and support from health or social services?	1	2	3	4, 5	2,436
40	Support from Health & Social Services	Once your cancer treatment finished were you given enough care and support from health or social services?	1	2	3	4, 5, 6	1,985
41	Other Support	Did healthcare professionals discuss with you or give you information about the impact cancer could have on your day-to-day activities?	1	-	2	3, 4	3,146
42	Other Support	Did healthcare professionals give you information about support or self-help groups for people with cancer?	1	-	2	3, 4	3,144

Question Number	Topic	Question Text	Positive values	Neutral values	Negative values	Excluded values	Number of responses analysed
43	Other Support	Did healthcare professionals give you information about how to get financial help or any benefits you might be entitled to?	1	-	2	3, 4	2,286
44	Other Support	Did healthcare professionals give your family or someone close to you all the information they needed to help care for you at home?	1	2	3	4, 5	2,898
45	Other Support	Do you feel you have been supported emotionally and psychologically by healthcare professionals during your cancer treatment?	1	2	3	4	3,604
46	Other Support	During your cancer treatment, have you been given information or support from third sector organisations?	1	-	2, 3	4, 5	2,618
47	Other Support	Do you feel you have been supported emotionally and psychologically by third sector organisations during your cancer treatment?	1	2	3	4	2,199
48	Other Support	Once your cancer treatment finished were you given information or support from third sector organisations?	1	-	2, 3	4, 5, 6	1,846
52	Overall Experience	Overall, how easy did you find it to travel to appointments relating to your cancer care?	1, 2	3	4, 5	-	4,725
54	Overall Experience	Were you able to bring a family member, friend or someone else to your appointments to support you when you wanted to?	1, 2	3	4, 5	6	4,335
55	Overall Experience	Overall, how would you rate the communication around how long appointments relating to your cancer care would take?	1, 2	3	4, 5	6	4,716

Question Number	Topic	Question Text	Positive values	Neutral values	Negative values	Excluded values	Number of responses analysed
56	Overall Experience	Overall, do you feel that you have been treated with dignity and respect by the healthcare professionals treating you for cancer?	1, 2	3	4	-	4,796
57	Overall Experience	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, 2	3	4, 5	6	4,786
58	Overall Experience	Did the different people treating and caring for you work well together to give you the best possible care?	1, 2	3	4	5	4,672
59	Overall Experience	Overall, how would you rate your care?	7, 8, 9, 10	4, 5, 6	0, 1, 2, 3	-	4,734

An Official Statistics Publication for Scotland

Official and National Statistics are produced to high professional standards set out in the Code of Practice for Official Statistics. Both undergo regular quality assurance reviews to ensure that they meet customer needs and are produced free from any political interference.

Correspondence and Enquiries

For enquiries about this publication please contact:

The Care Experience Survey Team,
Health and Social Care Analysis

Telephone: 0131 244 7552

e-mail: patientexperience@gov.scot

For general enquiries about Scottish Government statistics please contact:

Office of the Chief Statistician

Telephone: 0131 244 0442,

e-mail: statistics.enquiries@gov.scot

How to Access Background or Source Data

The data collected for this statistical publication are available in more detail through www.gov.scot/CancerSurvey.

Complaints and Suggestions

If you are not satisfied with our service or have any comments or suggestions, please write to the Chief Statistician, GR, St Andrew's House, Edinburgh, EH1 3DG, Telephone: (0131) 244 0302, e-mail: statistics.enquiries@gov.scot.

If you would like to be consulted about statistical collections or receive notification of publications, please register your interest at www.gov.scot/scotstat.

Details of forthcoming publications can be found at www.gov.scot/statistics.

Crown Copyright

You may use or re-use this information (not including logos) free of charge in any format or medium, under the terms of the Open Government Licence. See: www.nationalarchives.gov.uk/doc/open-government-licence/.



Scottish Government
Riaghaltas na h-Alba
gov.scot

© Crown copyright 2019



This publication is licensed under the terms of the Open Government Licence v3.0 except where otherwise stated. To view this licence, visit nationalarchives.gov.uk/doc/open-government-licence/version/3 or write to the Information Policy Team, The National Archives, Kew, London TW9 4DU, or email: psi@nationalarchives.gsi.gov.uk.

Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

This publication is available at www.gov.scot

Any enquiries regarding this publication should be sent to us at
The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-78781-780-7 (web only)

Published by The Scottish Government, April 2019

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDA577330 (09/17)