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Scottish Cancer Patient Experience Survey 2015/16: Technical Report

Scottish Care Experience
Survey Programme

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Contents

Introduction

The Scottish Cancer Patient Experience Survey is a postal survey conducted with the aim of establishing the experience of people aged 16 years and older who have received treatment for cancer in Scotland. This 2015/16 survey is the first time that the survey has been run.

The survey covers the care journey that a cancer patient experiences, from thinking that something might be wrong with them through to the support they received after hospital treatment. A copy of the questionnaire can be found in Appendix A.

The survey was administered across all 14 territorial NHS Boards as well as the Golden Jubilee National Hospital. Reports are produced for these 15 NHS Boards, the five cancer centres (Aberdeen Royal Infirmary, Beatson West of Scotland Cancer Centre, Edinburgh Cancer Centre, Ninewells Hospital, Raigmore Hospital), the three regional cancer networks (North of Scotland Cancer Network, South East Scotland Cancer Network, West of Scotland Cancer Network) and for Scotland as a whole.

This report provides technical information on the survey design, sampling, fieldwork and analysis of the 2015/16 survey. The survey results are available at:

http://www.gov.scot/cancersurvey

The other regular national care experience Surveys are:

- Inpatient Experience Survey
- Health and Care Experience Survey
- Maternity Care Experience Survey

A one-off Radiotherapy Survey was completed in 2014.

The Scottish Cancer Patient Experience Survey is jointly funded by the Scottish Government and Macmillan Cancer Support.

The survey is supported by Information Services Division (ISD) of NHS National Services Scotland. ISD's role included advising on survey methodology, securing approval from the Privacy Advisory Committee and Community Health Index Advisory Group to use patient information for the survey, sampling, producing national and local analysis and producing local level reports.

The administration of the survey fieldwork was undertaken by approved survey contractor Quality Health Ltd.

Aims of the Scottish Cancer Patient Experience Survey

The survey's aims are to:

- Provide comparative feedback to Regional Cancer Networks, Cancer Centres and NHS Boards that will be used to highlight areas of best practice, and to indicate where improvement work might need to be considered.
- Explore if there are differences in experience of treatment between groups of cancer patients (for example different cancer types and level of deprivation).
- Allow assessment of change in cancer care experience over time.

With respondent consent and the necessary approvals, results from the survey can in future be linked to data from other health and social care datasets by NHS Scotland statisticians. This would provide further insight into patients' experience of their care and treatments and link these to outcomes.

Outputs from the Cancer patient experience survey

National report

National level results from the survey were compiled in a written report published on the 6th of June 2016. It presents results for each survey question for Scotland as a whole.

As part of the analysis, results were broken down by the most common tumour groups and differences between the groups were tested for statistical significance. Where there were significant differences in results between tumour groups, this was presented in the national report.

Additionally, the report includes a summary of the differences between results from patients living in the most and least deprived areas of Scotland. This used the Scottish Index of Multiple Deprivation (SIMD) as the measure of deprivation.

National report

NHS Board, Regional Cancer Network, and Cancer Centre reports

Reports were published for the 14 territorial NHS Boards and Golden Jubilee National Hospital, as well as the three regional cancer networks and five cancer centres.

NHS Board, Regional Cancer Network and Cancer Centre reports

The format of these reports is similar to the sub-national reports published for the Inpatient Experience Survey, Health and Care Experience Survey and Maternity Care Survey.

The main focus of these reports is on the ‘percent positive. This is the percentage of people who answered each question in a positive way. For example, when asked whether they were given enough privacy when discussing their condition or treatment, if patients responded ‘Yes, always’ this was counted as a positive answer. ‘Yes, sometimes’ was considered a neutral/mixed answer and ‘No’ was considered a negative response.

A full description of which response options were classified as positive, neutral and negative are provided in Appendix B.

In the reports, colour-coded bar charts are used to show the percentage of respondents who responded positively, neutrally, and negatively for each question where this is appropriate.

The results are compared with the Scottish average. Differences from the Scottish national results that are statistically significant are shown with an '*s*' next to the percentage point change, e.g. $+4^{s}$ or -5^{s}.

In some cases either the number of positive responses or the number of responses that were not positive (ie the neutral and negative responses combined) were too low for the preferred statistical test (see Analysis and Reporting chapter) to be valid. In these cases, differences were marked 'NT' (Not Tested) to denote that no significance testing was done.

Results for questions where responses cannot reasonably be classed as 'positive' or 'negative' are presented in tables.

Further charts show the variation in percent positive scores between the different NHS Boards / Cancer Networks / Cancer Centres and further tables provide scores for the different tumour groups.

Analysis of free text comments

The free text comments made by patients as part of the survey have been analysed by academics based at the University of Stirling.

A report summarising the national findings for Scotland is available on the Scottish Government website:

Analysis of the freetext comments

Freetext comments have not been analysed at the level of NHS Boards, Regional Cancer Networks or Cancer Centres. However, NHS Boards and Regional Cancer Networks will be provided with the comments relevant to them.

Survey questionnaire

Introduction

The survey questionnaire (Appendix A) was based substantially on the questionnaire used for the most recent (2015) cancer patient experience survey in England. A limited number of changes were made to tailor the questionnaire to Scotland.

English questionnaire as basis

The content of the Scottish survey questionnaire was guided by the survey's Steering Group (the group membership is listed in Appendix F). When it emerged that a revised questionnaire was being developed for the equivalent survey in England, the Steering Group agreed that it would be advantageous to use this as the basis for the Scottish questionnaire. This had the benefit of maximising comparability between the two surveys as well as taking advantage of any learning that colleagues in England had gained from previous versions of their survey.

NHS England very kindly shared draft versions of their survey, allowing the Scottish questionnaire to be developed in tandem with their own.

Differences compared with the English questionnaire

A small number of changes were made to the English questionnaire linked below. The rationale for these changes is explained in Table 1 (overleaf).

(English) National Cancer Patient Experience Survey questionnaire

Table 1: Changes made to the English questionnaire

Change	Reason for change
Question relating to whether patient had been told that they could receive free prescriptions (Q23 in English questionnaire) was removed.	All patients receive free prescriptions in Scotland. This question was therefore not considered relevant.
A number of questions were added which asked: 'did [this aspect of care] take place at the hospital named on the covering letter?' (for example Q8 in Scottish questionnaire).	These questions were included to allow us to verify that different aspects of hospital care took place at the hospital we identified when selecting patients (see Analysis and Reporting chapter). This allowed us to correctly allocate survey responses, whilst still collecting the maximum data at the national level.
Instead of asking for overall comments at the end of the questionnaire, seven comments boxes were placed throughout the questionnaire. These comments boxes were targeted at specific aspects of their care.	There was significant interest within the survey steering group in the use of freetext comments and the additional information that they could provide. It was felt that an increased number of targeted comments boxes would provide more useful detail about patients' care and allow greater accuracy in attributing comments to particular aspects of the patient pathway.
Demographic questions	A number of changes were made to the demographic questions. These were made to bring the questions in line with the approach taken across other Government surveys in Scotland, including the other patient experience surveys.

Sample

Aims of sample

The sampling approach for the Cancer Patient Experience Survey was designed to:

- Provide national level results, NHS Board level results, Regional Cancer Network results and results for the five cancer centres in Scotland.
- Provide feedback relating to recent experiences
- Include people who had experienced the range of cancer care services
- Minimise the chances of sending the survey to individuals that did not have cancer or who had died since leaving hospital.

Sampling frame

The sampling for the survey was carried out by ISD.

Direct sampling from the Scottish Cancer Registry (SMR6) is not permitted for a postal survey of this sort. Therefore, the primary sampling frame was a national dataset containing records of acute hospital activity (SMR01). This was used to identify adults (aged 16 years and over) with an inpatient or day case record with any mention of cancer during the period between 1st January 2014 and 30th September 2014.

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. The sample identified from the hospital records was checked to identify patients who had a Cancer Registry diagnosis date between 1st July 2013 and 31st March 2014 and who were alive at 31st July 2015. Patients sampled from SMR01 but not present in SMR6 were excluded from the sample.

Criteria for exclusion from the sample.

The following patients were excluded from the sample:

- Patients aged 15 or less (on discharge from hospital).
- 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 other 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 (C44.0 to C44.9).
- Patients with an ICD10 code of C84 and all other C84 classifications (C84.0 to C84.9).
- Patients who do not have a confirmed diagnosis of cancer according to SMR06.

Sampling approach

Once the list of eligible patients was compiled, ISD eliminated duplications and incomplete records to determine the final sample frame.

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.

Data transfer

- ISD and the survey contractor ensured that all data was transferred securely via secure File Transfer Protocol (sFTP) with secure login. Once files were received they were immediately deleted from this system. The data transferred to the contractor included patient name and address and a unique identifier, generated for the specific purposes of this survey.

- The fields included in the data transfer were limited to those required to mail the survey pack to the individual patient and to identify which hospital they should complete the survey in relation to.

- On completion of the survey fieldwork and data capture the contractors sent the complete anonymised data files electronically to ISD through secure FTP. This enabled ISD to undertake analysis for the reporting.

Access to sampling frame and patient address information

To gain permission to use patient information for the survey (including sharing it with contractors for the purposes of administrating the survey) approval was required from two oversight groups. This process of gaining approval was led by ISD.

The two groups were:

- NHS NSS’s Privacy Advisory Committee – a committee which provided independent advice to NHS NSS and The Registrar General on the protection of privacy of patient information

- the Community Health Index (CHI) Advisory Group - a professional and lay group that advised on appropriate uses of the CHI number, which is a unique identifier held by every person in Scotland and which is applied to their health care records.

The Public Benefits and Privacy Panel has now taken over the functions of these groups. You can find more information on the Public Benefits and Privacy Panel and the principles guiding the use of patient data at the link below:

http://www.informationgovernance.scot.nhs.uk/

Fieldwork

Fieldwork activities

A survey contractor, Quality Health Ltd, was appointed through a pre-established Framework Agreement. This Framework Agreement was developed after a rigorous selection process run by NSS National Procurement.

Scottish Government and ISD staff provided day-to-day support to the contractor for the administration of the survey during the fieldwork period.

The contractor carried out the fieldwork element of the survey, organising the mail out of survey packs, sending weekly monitoring updates to ISD, Macmillan Cancer Support and the Scottish Government, issuing reminders, input and quality assurance of data and sending completed datasets to ISD.

The fieldwork commenced on 7th October 2015 with the initial survey packs containing the following:

- Introductory / Covering letter, backed with FAQs (Appendix C);
- Cancer Patient Experience Survey questionnaire (Appendix A);
- A sheet explaining in a variety of languages that translations were available via a helpline. This sheet also listed sources of support and information regarding cancer (Appendix D).
- FREEPOST envelope in which to return the survey.

Patients who did not wish to take part in the survey were advised that they could indicate this either by phoning the helpline number and leaving their details so that they could be removed from the mailing list or returning the uncompleted questionnaire using the FREEPOST envelope. This would ensure that they would receive no further correspondence.

Reminder letters were sent out twice during the fieldwork period to further encourage participation in the study. The initial reminder was sent on 29th October 2015 to patients who had not responded to the first mailing and who had not opted out. The first reminder pack consisted solely of a letter requesting the potential respondent complete the questionnaire sent in the original survey pack.

A second reminder was sent out on 19th November 2015 to patients who had not responded, and who had not otherwise been removed from the sample. This was approximately three weeks after the first reminder letter was issued. At this stage a full survey pack (including an additional copy of the questionnaire and a FREEPOST envelope) was re-issued along with the second reminder letter to make it easier for participants to respond.

The survey closed on 22nd January 2016.

Data entry and fieldwork quality control

Data entry and coding

The contractor was responsible for data entry and quality assurance of data collected during the survey.

With the exception of questions which allowed respondents to provide written comments, the Scottish Cancer Patient Experience Survey contained predefined answer options for respondents to tick as appropriate. Answer options corresponded to codes which were entered into the data file to indicate which answer had been selected by respondents for each question. A copy of the questionnaire is in Appendix A.

The contractor was also required to record responses where a patient answered a routing question and then continued to answer subsequent questions contrary to the routing instructions within the original routing question.

For questions where a written comment could be provided, guidance was agreed with contractors on how to handle these answers (Appendix E).

Data file processing

Once data had been collected, the contractor was able to establish a raw final data file containing all survey information including routing errors.

Once the raw data file had been developed by the contractor, the file was transferred to ISD to carry out analysis.

Quality assurance processes

Throughout the data entry process and prior to the data file being sent to ISD, the contractor was required to undertake data checks on data entered into the final data file.

Checks were made by two team members checking every tenth record to ensure that what was contained within the respondent’s completed version of the survey was verified against what had been entered within the data files.

Survey response

Response rate for the survey

The response rate for the survey is the number of completed forms returned as a percentage of the number of valid survey packs sent out. In total, 7,949 valid surveys were sent to patients and 4,835 were returned completed, giving an overall response rate of 61 per cent.

Survey packs were considered to be valid if they were successfully delivered to an eligible patient.

Of the 4,835 respondents:

- 4,297 sent their surveys back in the post
- 525 completed their survey online
- 11 completed their survey via the telephone helpline, and
- the remaining 2 completed the survey using the telephone translation helpline.

Response rates for individual NHS Boards, Regional Cancer Networks, and Cancer Centres

The NHS Board, Regional Cancer Network and Cancer Centre with highest response were NHS Borders, the North of Scotland Cancer Network and Ninewells Hospital respectively (Table 2, Table 3, Table 4).

Note: where the tables overleaf include numbers that are too low to report (less than 20) these instances have been marked with '**' .

Table 2: Response rate by NHS Board of treatment

NHS Board	Responded		Did not respond		Total	
	N	%	N	%	N	%
NHS Ayrshire & Arran	265	62%	162	38%	427	100%
NHS Borders	81	72%	31	28%	112	100%
NHS Dumfries & Galloway	78	59%	55	41%	133	100%
NHS Fife	195	58%	142	42%	337	100%
NHS Forth Valley	139	62%	87	38%	226	100%
NHS Grampian	544	66%	284	34%	828	100%
NHS Greater Glasgow & Clyde	1,471	57%	1,126	43%	2,597	100%
NHS Highland	284	67%	143	33%	427	100%
NHS Lanarkshire	278	56%	222	44%	500	100%
NHS Lothian	1,006	63%	584	37%	1,590	100%
NHS Orkney	**	**	**	**	**	100%
NHS Shetland	**	**	**	**	**	100%
NHS Tayside	380	66%	197	34%	577	100%
NHS Western Isles	**	**	**	**	**	100%
Golden Jubilee National Hospital	97	59%	67	41%	164	100%
Total	**4,835**	**61%**	**3,114**	**39%**	**7,949**	**100%**

Table 3: Response rate by Regional Cancer Network of treatment

Regional Cancer Network	Responded N	Responded %	Did not respond N	Did not respond %	Total N	Total %
North of Scotland Cancer Network	1,225	66%	638	34%	1,863	100%
South East Scotland Cancer Network	1,360	63%	812	37%	2,172	100%
West of Scotland Cancer Network	2,153	57%	1,597	43%	3,750	100%
Not part of a Network (Golden Jubilee National Hospital)	97	59%	67	41%	164	100%
Total	**4,835**	**61%**	**3,114**	**39%**	**7,949**	**100%**

Table 4: Response rate for Cancer Centre of treatment

Cancer Centre	Responded N	Responded %	Did not respond N	Did not respond %	Total N	Total %
Aberdeen Royal Infirmary	487	67%	242	33%	729	100%
Beatson West of Scotland Cancer Centre	576	60%	392	40%	968	100%
Edinburgh Cancer Centre	558	68%	268	32%	826	100%
Ninewells Hospital	325	69%	148	31%	473	100%
Raigmore Hospital	262	67%	130	33%	392	100%
Other hospitals	2,627	58%	1,934	42%	4,561	100%
Total	**4,835**	**61%**	**3,114**	**39%**	**7,949**	**100%**

Respondent burden

The survey should have taken respondents around 20 minutes to complete. The total respondent burden as defined by (number of responses) * (time taken to respond) is 1,612 hours.

Response analysis

The number of responses analysed for each question is typically lower than the total number of responses received. This is because not all of the questionnaires returned could be included in the calculation of results for every individual question. This was mainly for the following reasons:

- The specific question did not apply to the respondent and so they did not answer it. For example if the patient did not receive radiotherapy treatment they would not complete the questions relating to radiotherapy;

- The respondent answered that they did not know or could not remember the answer to a particular question;
- The respondent gave an invalid response to the question, for example they ticked more than one box where only one answer could be accepted.

Non-response

Opting out

A total of 570 respondents opted out of the survey, or were reported by a friend or relative as being too ill to take part. Patients could opt out of the survey by contacting the survey helpline or returning the questionnaire blank.

This was the only form of non-response where it was considered that an eligible patient had received a valid survey. These 570 individuals were therefore included in the calculation of the survey response rate.

Undeliverable

A total of 45 questionnaires were returned to the contractors as undelivered. It is possible that these patients no longer live at the address under which they are registered at their GP practice (this is the initial source of the address information used in the survey).

Deceased patients

As with all Care Experience surveys, every effort was made to avoid questionnaires being sent to family members of deceased people. Before the fieldwork began in earnest, ISD removed all patients appearing on the National Records of Scotland (NRS) deaths database from the sample.

A revised list of people included in the survey was sent to NHS Central Register (NHSCR) and to ATOS who administrate the CHI database.

On the morning of each mail out, NHSCR alerted ISD to any deaths that had been formally registered. In addition, ATOS were able to notify ISD of any deaths that were captured on the CHI database that had not yet been formally registered. For example, in situations where a GP has informed CHI of a patient’s death but the family of the deceased had yet to register the death.

ISD processed this information and supplied a list of deceased people to the contractors by noon each day of mail out.

Patients were also marked as deceased in situations where a relative of the patient had reported directly to the contractor that the patient had died.

The contractor removed the relevant letters/questionnaires from the mailing.

- Before the first questionnaires were sent, 48 people were identified as deceased and removed from the sample. These people were not sent survey questionnaires.

- Prior to the first and second reminders, 53 and 75 people respectively were identified as deceased and they were not sent further correspondence.

- In seven cases, patients were identified as deceased by a relative. However, this information was either not received, or the death was not registered, in time to prevent a survey questionnaire being sent.

Self-identified ineligible patients

- Over the course of survey fieldwork a total of 42 patients identified that they were not eligible to take part in the survey. This was typically through patients reporting that they had not received hospital treatment for cancer.

- In cases where a patient requested further information regarding their inclusion in the survey sample, staff from the patient’s NHS board of residence made every effort to contact the patient to discuss this.

Analysis and reporting

Analysis

The survey data collected and coded by the contractor were securely transferred to ISD via secure FTP and analysed using the statistical software package SPSS.

The analysis produced by ISD was transferred to the Scottish Government and Macmillan Cancer Support for inclusion in the national report.

Weighting the data

No weighting was applied to the survey data in any of the reporting formats. Unlike other Care Experience Surveys, which use stratified random sampling, this survey was a census of eligible patients.

There are ways that the data could be weighted using the differences in the characteristics of those sampled. However, historically patient experience survey results have only been weighted to allow for the different sizes of the strata alone.

Equivalent Cancer Patient Experience Surveys in other parts of the UK do not apply weighting.

Significance tests

Questions which produced ‘percent positive’ results were subject to significance testing to investigate differences between groups of respondents.

Differences between local level results and Scotland

For the purpose of the local level reports, significance testing was conducted to see if the results for each NHS Board, Cancer Network and Cancer Centre, were significantly different from the comparible figure for Scotland as a whole.

The method used to do this was the established approach used across the Care Experience Surveys:

Care Experience Surveys significance testing

This approach uses the normal approximation to the binomial theorem and is equivalent to constructing a 95% confidence interval for the difference between two results. If this confidence interval does not contain 0 then the result is statistically significant at the 5% level.

One point to note is that, given the census approach taken in survey, there is no design effect to take account of in the calculations.

Differences between most and least deprived areas

For the purposes of the national report, differences were tested between respondents from the most and least deprived SIMD quintile. This also followed the Care Experience Surveys standard approach (replacing Scotland and the local area in the calculation with the most and least deprived SIMD quintiles).

Differences between tumour groups

For the purposes of the national report, differences were tested between patients belonging to different tumour groups. A Pearson chi-square test was used to detect any statistically significant differences in the distribution of positive responses across all tumour groups ($\alpha = 0.05$). This excluded patients where the tumour group was unknown, or their tumour type was included in the 'other' category.

Where statistically significant differences were found across the tumour groups, significance testing was conducted to see if each tumour group was significantly different from the figure for all tumour groups (this is simply the Scotland figure). This was done using the standard approach referred above.

Reporting thresholds

Reports for NHS Boards, Regional Cancer Networks and Cancer Centres were only produced if there were 50 or more respondents. If a particular question had less than 20 responses, the results for that question were suppressed.

Allocation of survey results to the correct NHS Board, Regional Cancer Network or Cancer Centre

As set out in the chapter on sampling, each patient in the survey was selected to take part on the basis of a specific hospital visit. The name of the relevant hospital was printed on the covering letter that the patient received with the survey.

The starting basis for the allocation of patient responses was that patients were allocated to the i) hospital, ii) NHS board, and iii) regional cancer network results all based on this specific hospital.

For example, someone that was selected for the survey on the basis of an inpatient stay at Ninewells hospital in Dundee would appear in the results for: Ninewells hospital; NHS Tayside; and the North of Scotland Cancer Network.

There were two exceptions to this approach: i) for questions that did not relate to hospital care and ii) for questions where the respondent indicated that a particular aspect of their care did not take place at the hospital on the covering letter.

Questions not relating to hospital care

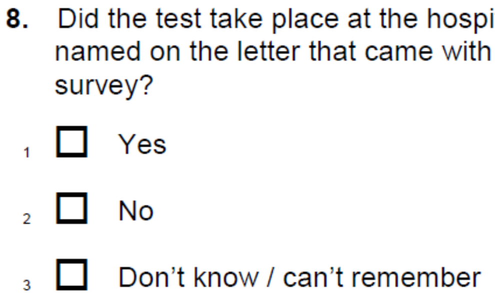
Cancer patients do not necessarily live in the same NHS Board that they receive hospital care. This is relevant as some of questions in the survey relate to care that an individual would have likely received at home or the area where they live.

In order to account for this:

- Questions 1, 2 and 3 were assigned to the NHS Board / Cancer Network that the patient lived in at the time of diagnosis (these questions related to patients approaching their GP at the point that cancer was suspected).
- Questions 55, 56 and 58 were assigned to the NHS Board / Cancer Network that the patient lived in at the time of their hospital treatment (these questions related to community-based health and social services and GP care during cancer treatment)

Care that took place at a different hospital

For each aspect of hospital care covered in the survey, the questionnaire offered the respondents the chance to confirm whether their care took place in the hospital on the covering letter.



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

1 ☐ Yes

2 ☐ No

3 ☐ Don’t know / can’t remember

In instances where respondents indicated that this was indeed the case, the results were assigned to hospitals, NHS Boards and Regional Cancer Networks on the basis of the hospital on the covering letter.

Where respondents indicated that they did not receive that aspect of treatment at the hospital on the covering letter, the results were not assigned to any hospital, NHS Board or Cancer Networks. It was not clear where the respondent had received this care, so responses for that aspect of hospital care were included only in the national level results.

Sources of bias

Non-response bias

The greatest source of bias in the survey estimates is due to non-response. Non-response bias will affect the estimates if the experiences of respondents differ from those of non-respondents.

Other sources of bias

There are potential differences in the expectations and perceptions of patients with different characteristics. Patients with higher expectations will likely give less positive responses. Similarly patients will perceive things in different ways which may make them more or less likely to respond positively. When making comparisons between geographical areas within Scotland it should be remembered that these may be affected by differences in patient characteristics across the geography’s cancer population.

In interpreting the results, consideration should also be given to differences in the nature of NHS Boards and Regional Cancer Networks in Scotland. Across NHS Boards, for example, there is a large variation in geographic coverage, population sizes and hospital sites as well as hospital type which should be borne in mind when reviewing survey findings.

Appendix A: Survey questionnaire

Cancer Patient Experience Survey

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

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

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

If you would prefer, you may also complete this survey online:
Go to www.quality- health.co.uk/scc15
Or scan the QR Code with your tablet / smartphone ➔

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

Instructions

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

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

☑ Yes
☐ No

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

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

Please return in the envelope provided or to:

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

SEEING YOUR GP

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

1. Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?

1 ☐ **None** – I went straight to hospital
2 ☐ **None** – I went to hospital following a cancer screening appointment
3 ☐ I saw my GP **once**
4 ☐ I saw my GP **twice**
5 ☐ I saw my GP **3 or 4** times
6 ☐ I saw my GP **5 or more** times
7 ☐ Don't know / can't remember

2. How do you feel about the length of time you had to wait before your **first appointment with a hospital doctor**?

1 ☐ I was seen as soon as I thought was necessary
2 ☐ I should have been seen a bit sooner
3 ☐ I should have been seen a lot sooner

3. How long was it from the time you first thought something might be wrong with you until you first saw a GP or other doctor?

1 ☐ Less than 3 months
2 ☐ 3 - 6 months
3 ☐ 6 - 12 months
4 ☐ More than 12 months
5 ☐ Don't know / can't remember

DIAGNOSTIC TESTS

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

1 ☐ Yes ➔ **Go to Q5**
2 ☐ No ➔ **Go to Q9**

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

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

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

6. Overall, how did you feel about the length of time you had to wait for your test to be done?

1 ☐ It was about right
2 ☐ It was a little too long
3 ☐ It was much too long
4 ☐ Don't know / can't remember

7. Were the results of the test explained in a way you could understand?

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

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

1 ☐ Yes

2 ☐ No

3 ☐ Don't know / can't remember

FINDING OUT WHAT WAS WRONG WITH YOU

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

1 ☐ Yes

2 ☐ No

3 ☐ It was not necessary

4 ☐ I was told by phone or letter

5 ☐ Don't know / can't remember

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

1 ☐ It was done sensitively

2 ☐ It should have been done **a bit** more sensitively

3 ☐ It should have been done **a lot** more sensitively

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

1 ☐ Yes, I completely understood it

2 ☐ Yes, I understood some of it

3 ☐ No, I did not understand it

4 ☐ Don't know / can't remember

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

1 ☐ Yes, and it was **easy** to understand

2 ☐ Yes, but it was **difficult** to understand

3 ☐ No, I was not given written information about the type of cancer I had

4 ☐ I did not need written information

5 ☐ Don't know / can't remember

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

DECIDING THE BEST TREATMENT FOR YOU

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

1 ☐ Yes, completely

2 ☐ Yes, to some extent

3 ☐ No

4 ☐ There was only one type of treatment that was suitable for me

5 ☐ Don't know / can't remember

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

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No, side effects were not explained

4 ☐ I did not need an explanation

5 ☐ Don’t know / can’t remember

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

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No, I was not offered any practical advice or support

4 ☐ Don’t know / can’t remember

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

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No, future side effects were not explained

4 ☐ I did not need an explanation

5 ☐ Don’t know / can’t remember

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

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No, but I would like to have been more involved

4 ☐ Don’t know / can’t remember

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

CLINICAL NURSE SPECIALIST

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

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

1 ☐ Yes **➔ Go to Q19**

2 ☐ No **➔ Go to Q21**

3 ☐ Don’t know / can’t remember **➔ Go to Q21**

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

1 ☐ Very easy

2 ☐ Quite easy

3 ☐ Neither easy nor difficult

4 ☐ Quite difficult

5 ☐ Very difficult

6 ☐ I did not try to contact my Clinical Nurse Specialist

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

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

SUPPORT FOR PEOPLE WITH CANCER

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

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

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

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

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

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

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

OPERATIONS

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

1 ☐ Yes ➔ **Go to Q25**
2 ☐ No ➔ **Go to Q28**

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

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

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

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

1 ☐ Yes, completely

2 ☐ Yes, to some extent

3 ☐ No, but I would have liked an explanation

4 ☐ I did not need an explanation

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

1 ☐ Yes

2 ☐ No

3 ☐ Don’t know / can’t remember

HOSPITAL CARE AS AN INPATIENT

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

1 ☐ Yes ➔ **Go to Q29**

2 ☐ No ➔ **Go to Q42**

Thinking about the LAST time you had an operation or stayed overnight <u>for cancer care</u>…

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

1 ☐ Yes, often

2 ☐ Yes, sometimes

3 ☐ No

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

1 ☐ Yes, in all of them

2 ☐ Yes, in some of them

3 ☐ No, in none of them

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

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No

4 ☐ No family or friends were involved

5 ☐ My family did not want to talk to a doctor

6 ☐ I did not want my family or friends to talk to a doctor

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

1 ☐ Yes, in all of them

2 ☐ Yes, in some of them

3 ☐ No, in none of them

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

1 ☐ There were always or nearly always enough on duty

2 ☐ There were sometimes enough on duty

3 ☐ There were rarely or never enough on duty

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

1 ☐ Yes, all of them did

2 ☐ Only some of them did

3 ☐ None of them did

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

1 ☐ Yes, always

2 ☐ Yes, sometimes

3 ☐ No

36. During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I had no worries or fears

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

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not have any pain

38. Overall, did you feel you were treated with respect and dignity while you were in hospital?

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

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

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

40. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

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

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

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

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

HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT

42. Have you been treated as an outpatient or day case **for cancer care**?

1 ☐ Yes ➔ **Go to Q43**
2 ☐ No ➔ **Go to Q46**

Thinking about the LAST time you attended hospital as a day patient or outpatient for <u>cancer care</u> …

43. While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not have any worries or fears

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

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

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

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

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

RADIOTHERAPY AND CHEMOTHERAPY

46. Have you had radiotherapy treatment?

1 ☐ Yes ➔ **Go to Q47**
2 ☐ No ➔ **Go to Q50**

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

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

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

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

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

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

50. Have you had chemotherapy treatment?

1 ☐ Yes ➔ **Go to Q51**
2 ☐ No ➔ **Go to Q54**

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

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

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

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

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

1 ☐ Yes
2 ☐ No
3 ☐ Don’t know / can’t remember

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

HOME CARE AND SUPPORT

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

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

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

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

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

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

CARE FROM YOUR GENERAL PRACTICE

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

1 ☐ Yes
2 ☐ No
3 ☐ Don’t know / can’t remember

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

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, they could have done more
4 ☐ My general practice was not involved

YOUR OVERALL NHS CARE

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

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

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

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

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

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

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

1 ☐ Much too long
2 ☐ A little too long
3 ☐ About right
4 ☐ Don’t know / can’t remember

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

1 ☐ Yes
2 ☐ No
3 ☐ No, but I would have liked them to
4 ☐ Don’t know / can’t remember

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

Very poor — Very good

0 1 2 3 4 5 6 7 8 9 10

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

YOUR CONDITION

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

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

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

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

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

67. Which of the following applies?

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

ABOUT YOU

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

68. What was your age on your last birthday?

☐

69. Are you male or female?

1 ☐ Male
2 ☐ Female

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

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

71. What is your ethnic group?
(*Tick* ***ONE*** *box which* ***best describes*** *your ethnic group*)

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

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

1 ☐ Work full time

2 ☐ Work part time

3 ☐ In full time education or training

4 ☐ Retired

5 ☐ Unemployed / looking for work

6 ☐ Don't work due to illness or disability

7 ☐ Other

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

1 ☐ Deafness or severe hearing impairment

2 ☐ Blindness or severe vision impairment

3 ☐ A physical disability

4 ☐ A learning disability

5 ☐ A mental health condition

6 ☐ Chronic pain lasting at least 3 months

7 ☐ Another long-term condition

8 ☐ None of the above

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

1 ☐ Yes, and I understand that this does **NOT** mean that I would have to take part in the survey

2 ☐ No, I would prefer you not to contact me again

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

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

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

1 ☐ Yes

2 ☐ No

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

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

1 ☐ Yes

2 ☐ No

Appendix B: Guide to Positive Scoring

Question number	Original Question Text	Positive	Neither positive nor negative	Negative
2	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	I was seen as soon as I thought was necessary	I should have been seen a bit sooner	I should have been seen a lot sooner
5	Beforehand, did you have all the information you needed about your test?	Yes		No, I would have liked more written information No, I would have liked more verbal information
6	Overall, how did you feel about the length of time you had to wait for your test to be done?	It was about right	It was a little too long	It was much too long
7	Were the results of the test explained in a way you could understand?	Yes, completely	Yes, to some extent	No, I did not understand the explanation I did not have an explanation but would have liked one
9	When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	Yes		No
10	How do you feel about the way you were told you had cancer?	It was done sensitively	It should have been done a bit more sensitively	It should have been done a lot more sensitively
11	Did you understand the explanation of what was wrong with you?	Yes, I completely understood it	Yes, I understood some of it	No, I did not understand it

Question number	Original Question Text	Positive	Neither positive nor negative	Negative
12	When you were told you had cancer, were you given written information about the type of cancer you had?	Yes, and it was easy to understand	-	Yes, but it was difficult to understand No, I was not given written information about the type of cancer I had
13	Before your cancer treatment started, were your treatment options explained to you?	Yes, completely	Yes, to some extent	No
14	Were the possible side effects of treatment(s) explained in a way you could understand?	Yes, definitely	Yes, to some extent	No, side effects were not explained
15	Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	Yes, definitely	Yes, to some extent	No, I was not offered any practical advice or support
16	Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	Yes, definitely	Yes, to some extent	No, future side effects were not explained
17	Were you involved as much as you wanted to be in decisions about your care and treatment?	Yes, definitely	Yes, to some extent	No, but I would like to have been more involved
18	Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	Yes	-	No
20	When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	All or most of the time	Some of the time	Rarely or never

Question number	Original Question Text	Positive	Neither positive nor negative	Negative
21	Did hospital staff give you information about support or self-help groups for people with cancer?	Yes		No, but I would have liked information
22	Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?	Yes		No, but I would have liked a discussion or information
23	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	Yes		No, but I would have liked information
25	Beforehand, did you have all the information you needed about your operation?	Yes		No, I would have liked more written information No, I would have liked more verbal information
26	After the operation, did a member of staff explain how it had gone in a way you could understand?	Yes, completely	Yes, to some extent	No, but I would have liked an explanation
29	Did groups of doctors and nurses talk in front of you as if you weren't there?	No	Yes, sometimes	Yes, often
30	Did you have confidence and trust in the doctors treating you?	Yes, in all of them	Yes, in some of them	No, in none of them

Question number	Original Question Text	Positive	Neither positive nor negative	Negative
31	If your family or someone else close to you wanted to talk to a doctor, were they able to?	Yes, definitely	Yes, to some extent	No
32	Did you have confidence and trust in the ward nurses treating you?	Yes, in all of them	Yes, in some of them	No, in none of them
33	In your opinion, were there enough nurses on duty to care for you in hospital?	There were always or nearly always enough on duty	There were sometimes enough on duty	There were rarely or never enough on duty
34	While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	Yes, all of them did	Only some of them did	None of them did
35	Were you given enough privacy when discussing your condition or treatment?	Yes, always	Yes, sometimes	No
36	During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	Yes, definitely	Yes, to some extent	No
37	Do you think the hospital staff did everything they could to help control your pain?	Yes, definitely	Yes, to some extent	No

Question number	Original Question Text	Positive	Neither positive nor negative	Negative
38	Overall, did you feel you were treated with respect and dignity while you were in hospital?	Yes, always	Yes, sometimes	No
39	Were you given clear written information about what you should or should not do after leaving hospital?	Yes	-	No
40	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Yes	-	No
43	While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?	Yes, definitely	Yes, to some extent	No
44	The last time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?	Yes	-	No
47	Beforehand, did you have all of the information you needed about your radiotherapy treatment?	Yes, completely	Yes, to some extent	No
48	Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	Yes, completely	Yes, to some extent	No
51	Beforehand, did you have all of the information you needed about your chemotherapy treatment?	Yes, completely	Yes, to some extent	No

Question number	Original Question Text	Positive %	Neither positive nor negative %	Negative %
52	Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	Yes, completely	Yes, to some extent	No
54	Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	Yes, definitely	Yes, to some extent	No
55	During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	Yes, definitely	Yes, to some extent	No
56	Once your cancer treatment finished were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	Yes, definitely	Yes, to some extent	No
57	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	Yes	-	No
58	Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	Yes, definitely	Yes, to some extent	No, they could have done more

Question number	Original Question Text	Positive %	Neither positive nor negative %	Negative %
59	Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?	Yes, always Yes, most of the time	Yes, some of the time	No, never
60	Have you been given a care plan? A care plan is a document that sets out your needs and goals for caring for your cancer. It is an agreement or plan between you and your health professional to help meet those goals.	Yes	-	No I do not know / understand what a care plan is
61	Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc)?	Very good Good	Neither good nor bad	Quite bad Very bad
62	Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	About right	A little too long	Much too long
63	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	Yes	-	No No, but I would have liked them to
64	Overall, how would you rate your care (rating from 1 to 10)?	7,8,9,10	4,5,6	0,1,2,3

Appendix C: Survey materials – Covering Letter

healthier scotland
SCOTTISH GOVERNMENT

WE ARE MACMILLAN. CANCER SUPPORT

NHS SCOTLAND

helpline

For survey queries:
0800 7831775

Monday-Friday
9am-5pm

For other sources of information please see enclosed patient leaflet

Dear First Name Last Name

We would like to ask you to take part in a survey about your experience of cancer care and treatment. Your views are important as they will help us understand more about the quality of NHS services for cancer patients and let us know what needs to be improved.

If you think that this survey is not appropriate for you, because you have not had a cancer diagnosis, we apologise for contacting you. Please let us know that this is the case using the FREEPOST envelope provided or using the FREEPHONE helpline number above.

If you are happy to participate you can complete the survey online at: **www.quality-health.co.uk/scc15**
Username: XXXXX. Password

Alternatively you can complete the enclosed questionnaire and return it in the FREEPOST envelope provided.

You do not have to participate and your care will not be affected in any way by whether you decide to participate or not. Your care team will not know if you have participated and will not have access to any identifiable patient responses.

In some of the survey questions we ask whether the care you received took place at the hospital named on this covering letter. For these questions, the specific hospital we are asking about is:

NHS Site A in NHS Board A

You will receive a reminder in a couple of weeks if you have not responded to the survey. So if you wish to take part, please respond as quickly as possible so that we can avoid troubling you with a reminder.

Alternatively, if you do not want to take part, you can opt out by returning the questionnaire blank in the FREEPOST envelope provided or by calling the FREEPHONE helpline. **You do not need to provide any reason for deciding not to participate.**

Thank you very much for your time.

Yours sincerely

Medical Director NHS Board Name	Clinical Lead Regional Cancer Network

Please turn over for more information

Some Questions & Answers

What happens to the results?
The results will be used to identify ways to improve cancer care in Scotland. We will give NHS boards and larger hospitals a summary report on their results so they can see how they are doing. You will be able to find the survey results in June 2016 at www.gov.scot/cancersurvey

I've received cancer treatment at more than one hospital or GP practice; which should I refer to?
For some questions, we ask you to refer to your most recent treatment or experience. For the other questions please refer to your recent experiences overall.

Can someone help me with the survey?
Yes, a relative, friend or carer may help you to fill in the survey, but please remember that all of the answers should be given from your own point of view. If you would prefer, you can give your answers over the phone instead, by calling the FREEPHONE helpline on **0800 783 1775**. The person on the phone will need you to tell them the ID number that is on the front of this letter.

Do I have to answer every question?
Taking part is voluntary and if you do, you don't have to answer every question. Sometimes we will ask you to skip a question if it doesn't apply to you.

Do I have to take part?
No, you don't have to take part if you don't want to, but taking part should help us to improve the care provided for everyone. If you would prefer not to receive any more letters or reminders about the survey, please phone the helpline on **0800 783 1775** or return the questionnaire blank. Your care will not be affected in any way by whether you decide to participate or not.

Will the people involved in my care see my answers?
NHS staff will not know if you have taken part in the survey. We will group together replies from all the patients from each NHS Board or hospital and will only share these overall results. Any written comments you provide will be anonymised before being sent to those involved in your care along with all the other comments for that NHS Board or hospital.

How did you get my name and address?
NHS Scotland stores your contact details securely and confidentially under the terms of the Data Protection Act and other legislation.

The use of patient information for surveys such as this is considered by the Privacy Advisory Committee- http://www.nhsnss.org/pages/corporate/privacy_advisory_committee.php (now the Public Benefit and Privacy Panel-http://www.informationgovernance.scot.nhs.uk/). These groups advise on whether there is sufficient public benefit in using patient information in this way.

Your contact details have been passed to a patient survey contractor, Quality Health, only so that they can send you this questionnaire. Quality Health does not have access to any of your medical records and your contact details will be destroyed by the contractor once they have posted the questionnaire and any reminder letters to you.

translations	Textphone	online
0800 783 1775	0800 028 5695	www.quality-health.co.uk/scc15

Appendix D: Survey materials – Language / Information Sheet

healthier scotland
SCOTTISH GOVERNMENT

WE ARE MACMILLAN. CANCER SUPPORT

NHS SCOTLAND

If you feel that you need help, advice and/or have any questions with any of the issues raised in the questionnaire that you want to discuss with a health professional, the web address below can help you can find information about your local health services:

www.nhs24.com/FindLocal

WE ARE MACMILLAN. CANCER SUPPORT

☎ Need to talk? Call us >
0808 808 00 00
Monday to Friday, 9am-8pm

Questions about cancer? We can help. Macmillan Cancer Support are available to talk over the phone or online when you need us. Whether you're worried about money or practical issues, have questions about treatment, or just want someone to listen, call us on 0808 808 0000, Monday to Friday, 9am –8pm.

You can also find more information at our website: www.macmillan.org.uk

A range of information on cancer is available in the Cancer Zone of **NHS Informs**:

www.nhsinform.co.uk/cancer/

0800 22 44 88

If you need help with this survey in your own language, please call the Freephone helpline on 0800 783 1775

TEXTPHONE
0800 0285 695

Ma tha feum agad air cobhair na do chànan fhèin cuir fios chun t-saor-fòn taiceil air 0800 783 1775.

إذا كنت تحتاج إلى تلقي المساعدة في هذا الاستبيان بلغتك، يرجى الاتصال بخط المساعدة المجاني على رقم 0800 783 1775.

আপনার যদি এই সমীক্ষাটির ব্যাপারে নিজের ভাষায় সহায়তা প্রয়োজন হয়, অনুগ্রহ করে, ফ্রিফোন হেল্পলাইন নং 0800 783 1775 তে ফোন করুন।

倘若您需要用您的母語為您提供有關此調查的幫助，請撥打免費電話幫助熱線：0800 783 1775。

اگر این سروی را به زبان خود می خواهید، در خط تلفون مجانی با این شماره به تماس شوید: 0800 783 1775

જો તમને આ સર્વેક્ષણ અંગે તમારી ભાષામાં સહાય જોઈતી હોય તો, કૃપા કરી નિ:શુલ્ક હેલ્પલાઈનના 0800 783 1775 નંબર પર ફોન કરો.

Pour pouvoir répondre dans votre propre langue, demandez de l’aide gratuitement au 0800 783 1775.

Falls Sie für diese Studie Hilfe in Ihrer eigenen Sprache benötigen, rufen Sie uns bitte kostenlos an: 0800 783 1775.

Αν χρειάζεστε βοήθεια με την έρευνα αυτή στη γλώσσα σας, καλέστε δωρεάν το 0800 783 1775.

अगर आपको इस सर्वेक्षण के बारे में अपनी भाषा में मदद चाहिए, तो कृपया 0800 783 1775 पर फ्रीफोन हेल्पलाइन को कॉल करें।

Heke ûn pêvîstî heye ku vê pirsyarnameye bi zimana xwe wergirn ji kerema xwe bi hêla telefonê bixoraî ji bo yarmetî danê bi hejmara 0800 783 1775 pêvendî bkin.

Se avete bisogno di aiuto con il presente sondaggio nella vostra lingua, siete pregati di chiamare il numero verde 0800 783 1775.

如果您需要用您的母语为您提供有关此调查的帮助，请拨打免费电话服务专线：0800 783 1775。

Aby uzyskać pomoc dotyczącą tej ankiety w Twoim języku, zadzwoń na bezpłatną infolinię 0800 783 1775.

Se desejar assistência com este inquérito na sua língua, por favor ligue para a linha de assistência gratuita: 0800 783 1775.

ਜੇ ਤੁਹਾਨੂੰ ਇਸ ਸਰਵੇਖਣ ਬਾਰੇ ਤੁਹਾਡੀ ਆਪਣੀ ਭਾਸ਼ਾ ਵਿੱਚ ਮਦਦ ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ 0800 783 1775 ‘ਤੇ ਮੁਫਤਫੋਨ ਮਦਦਲਾਈਨ ਨੂੰ ਕਾਲ ਕਰੋ।

Nếu cần giúp đỡ khảo sát này bằng tiếng nói của quý vị, xin điện thoại bằng đường dây giúp đỡ miễn phí số 0800 783 1775

Чтобы получить информацию об этом исследовании на вашем родном языке, позвоните на бесплатную телефонную линию службы поддержки 0800 783 1775.

Haddii aad u baahan tahay in luqaddaada laguugu caawiyo indha-indhayntaan, fadlan wac khadka caawinta ee bilaashka ah 0800 783 1775.

Si necesita ayuda con esta encuesta en su   idioma, rogamos que llame a la línea de ayuda gratuita, tel.: 0800 783 1775.

இந்த கருத்தாய்வு நீங்கள் பேசும் மொழியில் தேவையெனில், தயவுசெய்து இலவச தொலைபேசி உதவியழைப்பை 0800 783 1775 என்ற எண்ணில் அழையுங்கள்.

Bu anketle ilgili kendi dilinizde yardıma ihtiyacınız olursa, lütfen 0800 783 1775 numaralı telefondan ücretsiz yardım hattını arayın.

اگر آپکو اس سروے کیلئے اپنی زبان میں مدد کی ضرورت ہو تو، براہ کرم فری فون ہیلپ لائن کو 0800 783 1775 پر فون کریں۔

Bi o ba nilo iranlowo ni ede re nipa iwadi yi, jowo pe ero ibanisoro ofe yi 0800 783 1775.

Në se ju duhet ndihmë për pyetësorin në gjuhën tuaj, ju lutem telefononi falas numrin 0800 783 1775.

Appendix E: Contractor Guidance on Patient Comments

Proofing comments

- The file will need to be spell checked in the first instance – firstly using the spell check facility in excel (ensuring it is on English UK).

- Each comment must then be thoroughly proof read to correct any further spelling mistakes, typos, issues with punctuation. Do not correct the comment for grammatical errors – the comment should be presented as the respondent has written it, even if it is grammatically incorrect. This process must be done carefully and without changing the original context of the comment.

- A key part of the proofing process is to ensure that comments have been properly anonymised to ensure the respondent's identity is protected. This involves removing any personal details or references including any staff / patient / ward / unit names or any other specifically detailed information such as diagnosis or tests or procedures done that could allow the respondent to be identified. Hospital names can be left in unless you are specifically instructed not to include these. This level of anonymisation should have taken place when the comments were first typed and you should see examples of this throughout the file where identifiable details have been removed and replaced with the following types of references - [name removed] / [job title removed] / [details removed]. These references should always appear in square brackets like this [ ] – if they are in normal brackets then please replace these with the square brackets for consistency. If you find instances of personal details that have not been successfully removed (unless there are specific instructions to leave them in for the particular survey you are working on), then please remove these details and replace them using the formulation described above. If in doubt, please seek clarification from a manager. Therefore, the following example alternatives should be used using the square brackets shown below:

Identifiable Information	Example of substitution
Mary Jones was in the bay beside me	Patient [name removed] was in the bay beside me
Nurse Smith was very nice	Nurse [name removed] was very nice

Dr I. Smith was very nice	Dr. [initial and name removed] was very nice
I did not like Dr Brown's bedside manner	I did not like Dr [name removed] bedside manner
I work as a male midwife on Trinity Ward	I work as a [job title removed] on Ward [name removed]
My Manager is the Director of Nursing and I have been abused and bullied	My Manager is the [name/title removed] and I have been abused and bullied
Date e.g. 10/05/2013	[date removed]
Mention of correspondence e.g. "official complaint", "letter to NHS Board", "letter to newspaper.	[correspondence removed]
Exact ages e.g. 29, eighteen	[age removed]

- If you cannot identify a word then you can type [word unreadable].
- Any obscenities should be replaced with [obscenity removed].
- You need to enter data in all comments boxes available before you can move to the next survey – for any blank boxes use a full stop.
- Do not use CAPITAL letters.
- reversed letter e.g. "teh" rather than "the" and other typos "i" rather than "I". Amend as necessary.
- When reading each comment in its entirety, it should be 'sense checked' to identify any unusual circumstances, detailed description of events or other very specific detail which could potentially lead to a person being identified. If any such reference is present, it should be removed to protect the identity of the respondent.
- Any comments which may need escalating under the Duty of Care policy should be immediately raised with a Manager – these include examples of respondents talking about allegations of abuse, self-harm, harm to others or suicide.

- If you are in doubt at all about the application of any of these rules against a specific comment, please ask for a 2nd opinion from a Manager – it is always better to check than risk revealing a respondents identity. You will have the final check on this document before it is sent to the client so it is important that these rules are followed thoroughly and carefully to fully protect the identity of all participants.

Appendix F: Members of Survey Steering Group

The following individuals were members of the steering group during the course of the development and implementation of the survey. The organisations listed reflect the individual's organisation during that period.

- Dr David Linden, Scottish Government (Chair)
- Sandra Bagnall, South of Scotland Cancer Network (SCAN)
- Dr David Brewster, NHS National Services Scotland, Information Services Division
- Sandra Campbell, NHS Forth Valley
- Shirley Fife, NHS Lothian
- Alistair Haw, Prostate Cancer UK
- Dr Emma McNair, NHS National Services Scotland, Information Services Division
- Gregor McNie, Cancer Research UK
- Shaun Maher, Scottish Government
- Rahana Mohammed, Prostate Cancer UK
- Kate Seymour, Macmillan Cancer Support
- Brian Sibbald, Patient Representative
- Joanna Swanson, Scottish Government
- Prof Mary Wells, Stirling University

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For general enquiries about Scottish Government statistics please contact:
Office of the Chief Statistician, Telephone: 0131 244 0442,
e-mail: statistics.enquiries@scotland.gsi.gov.uk

Complaints and suggestions

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

If you would like to be consulted about statistical collections or receive notification of publications, please register your interest at http://www.gov.scot/Topics/Statistics/scotstat. Details of forthcoming publications can be found at http://www.gov.scot/Topics/Statistics

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