



Scottish Radiotherapy Patient Experience Survey 2014: National Results: Volume 1

An official statistics publication for Scotland published by the Scottish Government



Scottish Care Experience
Survey Programme.

**SCOTTISH RADIOTHERAPY
PATIENT EXPERIENCE SURVEY 2014
NATIONAL RESULTS**

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Scottish Government
2014

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1 EXECUTIVE SUMMARY

Background

- 1.1 Over 1,400 patients responded to a questionnaire about their experience of undergoing radiotherapy treatment in Scotland during the period of 11 February 2014 to 4 July 2014. Most of the questions were based on similar (or identical) questions that were been used in a similar survey in England in 2012. The questions covered consent, information before radiotherapy treatment, website information, “about your radiotherapy”, daily treatment visits, information about support, following treatment, and overall experience.

Patients are positive about their overall radiotherapy care

- 1.2 Patients were broadly positive about their overall radiotherapy care. 97% of patients rated their overall care as excellent or very good, with 82% rating their overall care as excellent.
- 1.3 Patients were particularly positive about the staff: 91% of patients said that staff always took account of what mattered to them (and another 8% said that this was sometimes the case); and 97% of patients said that staff always treated them with compassion and understanding (and another 3% said that this was sometimes the case).

There is room for improvement

- 1.4 But there is room for improvement. Around a quarter (25%) of patients said that either they were only involved ‘to some extent’ (21%) or ‘not as much as they wanted’ (4%) in decisions about their care and treatment
- 1.5 Over one third of patients (37%) indicated that either the amount of information given at the start of their radiotherapy was only ‘satisfactory’ (36%) or was ‘poor’ (1%). Over one quarter of patients (26%) indicated that hadn’t had a regular formal review of their treatment.
- 1.6 Across the five radiotherapy centres results were broadly similar but there were some areas where there was considerable variation. This was particularly around:
- whether or not it was easy to park at the hospital/clinic
 - whether the changing facilities allowed patients to maintain dignity
 - whether patients had a regular formal review of treatment
 - whether patients were given a number to call if they had problems in relation to their radiotherapy, and
 - whether patients were given written information on what to expect following treatment and post treatment care

Consent for Radiotherapy

- 1.7 Patients were generally positive about many aspects of consent for treatment. Nevertheless, in many areas there are still significant numbers of patients for whom consent isn't being properly managed, and who are therefore only satisfied to some extent. This is particularly the case around satisfaction with the way patients' questions are answered (15% of patients were only satisfied to some extent) – and some patients said that they weren't given the opportunity to ask questions at all.
- 1.8 Similarly a large proportion of patients report that when giving consent they are not completely aware of the side effects (33% understood 'to some extent') and benefits of radiotherapy (23% understood 'to some extent').

Information before radiotherapy treatment

- 1.9 Patients were generally very positive about the information provided before radiotherapy treatment. But a number of patients said that they didn't get enough written information before their radiotherapy treatment (14%), and/or that it wasn't of the right quality to help with their treatment (2%).
- 1.10 Most patients (77%) were invited to the radiotherapy department before they started treatment, and virtually all of these (98%) found this helpful.

Website information

- 1.11 A minority of patients (16%) looked for information about radiotherapy on hospital websites. But the vast majority of those who did find it very helpful (69%) or fairly helpful (30%).
- 1.12 Of those patients who didn't look for information on hospital websites, a large proportion (26%) said that they didn't have internet access; and 19% said that they didn't know there was information there.

About your radiotherapy

- 1.13 It's encouraging that the vast majority of patients (97%) said that they were told very clearly how many fractions they would need. Nevertheless a sizeable proportion of patients indicated that they weren't told clearly how long their treatment would last (5%); weren't given a very clear explanation of their plan of treatment (10%); or weren't given very clear information to help manage their side-effects (27%). Over one in 10 (13%) indicated that they were given different information at their treatment visit than at their clinic visit.
- 1.14 97% of patients who wanted someone to talk to in hospital about their worries and fears said that they were able to find someone.

Daily treatment visits

- 1.15 Virtually 100% of patients said that the environment of the radiotherapy department (the waiting room, the treatment room, and the department as a whole) was “good” or “very good”.
- 1.16 There were some logistical issues, where patients were less positive (car parking, being informed of delays, and changing facilities). There is room for improvement on a number of questions to do with communication. The majority of patients are having formal reviews of their treatment, but for just over one-quarter (26%) this is not the case.

Information about support

- 1.17 Of those patients who were given information about support or self-help groups, the biggest proportion (39%) were given information about general cancer support groups in their area. 17% of patients said they would have liked information about support or self-help groups, but didn't get any.

Following treatment

- 1.18 Whilst many patients said that they were given a range of information and advice following treatment, for some patients this needs to be improved.
- 1.19 Most patients said that they were given a number to call to see if they had any problems following treatment, but 13% said that they weren't. 15% of patients said that they didn't know what the arrangements were for their next visit. And 44% of patients said that they were not given written information about what to expect in the weeks following treatment.

Results are broadly similar to English survey

- 1.20 Comparisons of the Scottish survey with the English results have found more similarities than differences between patients' experiences of radiotherapy care. Both report that patients are in the main positive about their radiotherapy care and treatment.
- 1.21 Where Scottish patients are more positive than English patients is around the environment of the radiotherapy department, and the overall experience of radiotherapy care. Areas where Scottish patients are less positive relate to written information given before and after treatment.

2 INTRODUCTION

- 2.1 The first Scottish Radiotherapy Survey 2014 took place between February and July 2014. It was administered through all five Scottish radiotherapy centres, with staff handing it out to patients who had undergone their final radiotherapy treatment. Patients only received one copy of the questionnaire and no reminders were issued.
- 2.2 The survey asks about people's experiences of: consent, information received before radiotherapy treatment, website information, radiotherapy treatment, information given about support, information following treatment and overall radiotherapy care.
- 2.3 The survey was based on the English Radiotherapy Survey which took place during 2012 with some minor amendments to the questions. This has enabled some high level comparisons between the English survey results and the Scottish survey results.
- 2.4 This report presents the detailed national findings from the survey. Results for each of the radiotherapy centres are available at:
<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/RadiotherapySurvey>

Aims of the Scottish Radiotherapy Survey 2014

- 2.5 The survey's specific aims are:
- To provide radiotherapy centres with feedback on the experiences of their patients, relative to other radiotherapy centres in Scotland in order to inform local improvements.
 - To provide national results for the survey to inform improvements for national policy.
 - To highlight areas of best practice and areas for improvement.
 - To provide a benchmark with the results of the English survey.

Survey design

- 2.6 The Scottish Radiotherapy Survey was based on the English version of the survey which was carried out in 2012 which enabled the results of the Scottish survey to be directly comparable with the English results, as required. A copy of the questionnaire is contained in [Appendix C](#).

Survey fieldwork and response

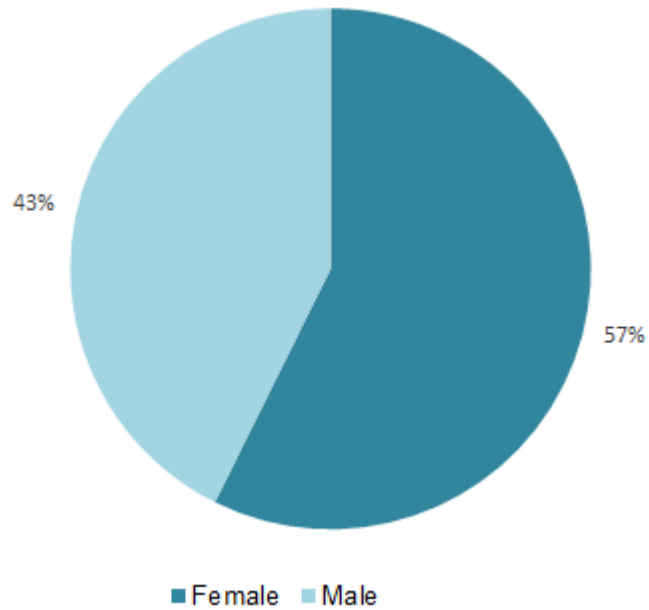
- 2.7 Fieldwork was undertaken by Quality Health Ltd, an approved patient survey contractor on behalf of the Scottish Government. Surveys were distributed directly by radiotherapy staff in the centres, and survey packs were sent to each of the centres by Quality Health.

- 2.8 The survey packs included a covering letter, copy of the questionnaire, reply paid envelope and a language leaflet. Packs were sent to the five radiotherapy centres: Inverness, Aberdeen, Dundee, Edinburgh and Glasgow. Inverness started distributing packs in February 2014, with the other four centres starting in March 2014.
- 2.9 The total number of questionnaires given out was 2556, with each centre receiving a quantity of packs according to the numbers of patients using the centre. The total numbers given out per centre were: Inverness – 224, Aberdeen – 398, Dundee – 334, Edinburgh – 650, Glasgow – 950.
- 2.10 Staff in the centres submitted a weekly total of patients who had finished treatment, and the numbers of those patients who had been given a questionnaire. It was this figure (number of questionnaires given out) that was used to calculate the response rate.
- 2.11 The questionnaires were returned by patients using the reply paid envelope included in their pack
- 2.12 Glasgow finished distribution of surveys in May, and Edinburgh in June since the number of patients attending those centres was higher. The distribution of survey packs continued in the other centres until July 2014. The cut off point for completed surveys to be returned to Quality Health was 29 August 2014.
- 2.13 The final response rate was 54%, with the highest response from Inverness (60%) and the lowest from Glasgow (49%). Given that there were no reminders for the survey and that the survey was handed out within the centres, this is a very good response rate.

Demographics of respondents

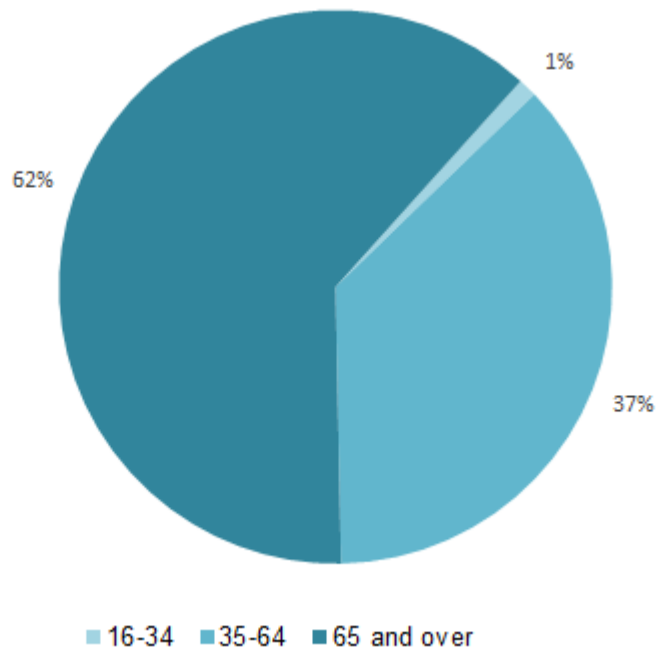
- 2.14 We asked patients a number of questions about their demographic characteristics. Of those patients who answered these questions:
- 2.15 57 per cent were female and 43 per cent were male (chart 1). The figures suggest that there is an over representation of women in the survey given that radiotherapy attendees tend to be fairly evenly split between males and females.

Chart 1 Demographics of respondents – Gender (%)



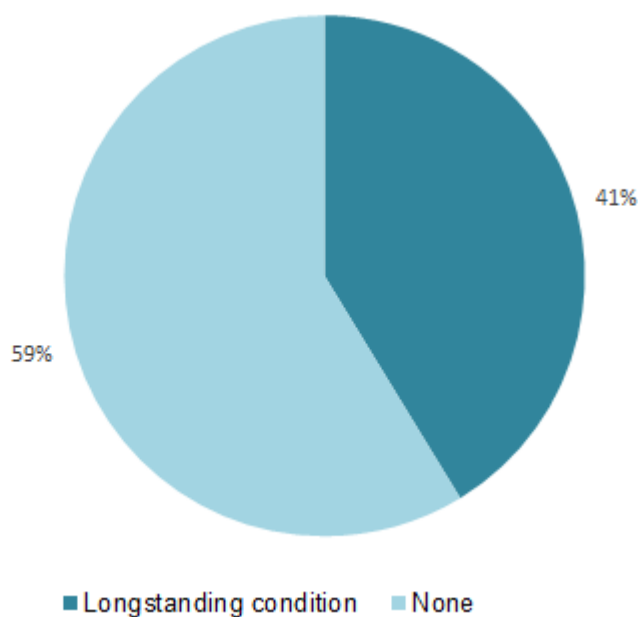
2.16 1 per cent were aged 16-34, 37 percent were aged 35-64, and 62 per cent were aged 65 and over (chart 2). Although radiotherapy patients are generally older, the figures suggest that there is an over representation of older people in the survey.

Chart 2 Demographics of respondents – Age (%)



2.17 41 per cent of people indicated that they had a longstanding health condition, whilst 59 per cent indicated they did not (chart 3).

Chart 3 Demographics of respondents – Longstanding Conditions (%)



Data analysis and interpretation

- 2.18 The survey data was collected and analysed by the contractor Quality Health Ltd.
- 2.19 In general, results are presented as percentage of patients reporting a positive experience. Such percentages are calculated excluding any patients from the denominator who did not answer the question or answered “not relevant or don’t know”. Information on which answers were classed as positive, partly positive, neutral and negative for each question can be found in [Appendix B](#).
- 2.20 Throughout the report, weighted percentages have been presented unless otherwise stated. Weights are applied to all survey responses based on the number of patients who were treated per centre during a defined time period. This means that the contribution of each centre to the national results is proportional to the number of patients that were eligible for the survey. Further information on how weights were calculated will be published in a technical report at:
<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/RadiotherapySurvey>

3 RESULTS – CONSENT FOR RADIOTHERAPY

Summary

3.1 Responses from patients on radiotherapy consent were mixed. Patients were particularly positive about being given the opportunity to ask questions and being treated with dignity and respect as well as confidence in the staff taking consent. But on many questions there are some patients for whom consent isn't being properly managed, and who are therefore only satisfied to some extent. This is particularly the case around satisfaction with the way patients' questions are answered (15% of patients were only satisfied to some extent). Similarly a large proportion of patients report that when giving consent they are not completely aware of the benefits (23% understood 'to some extent') and side effects of radiotherapy (33% understood 'to some extent').

Detailed results

3.2 Patients were asked about various aspects of consent including the provision of information about radiotherapy benefits and side-effects, the opportunity to ask questions and staff involved in consent. The results for these questions are summarised in table 1.

Table 1 Summary of the results to questions about consent

Measure	Negative	Neutral	Partly Positive	Positive
Understood the benefits of radiotherapy	0	23	n/a	76
Understood what the side-effects of radiotherapy were	2	33	n/a	65
Given the opportunity to ask questions before giving consent	2	n/a	n/a	98
Satisfied with answers received to questions	0	15	n/a	85
Had confidence in doctors or other health professional who took consent for radiotherapy	1	7	n/a	93
Treated with dignity and respect by the doctor or other health professional who took consent for radiotherapy	0	3	n/a	96

Note: percentages may not add up to 100% due to rounding

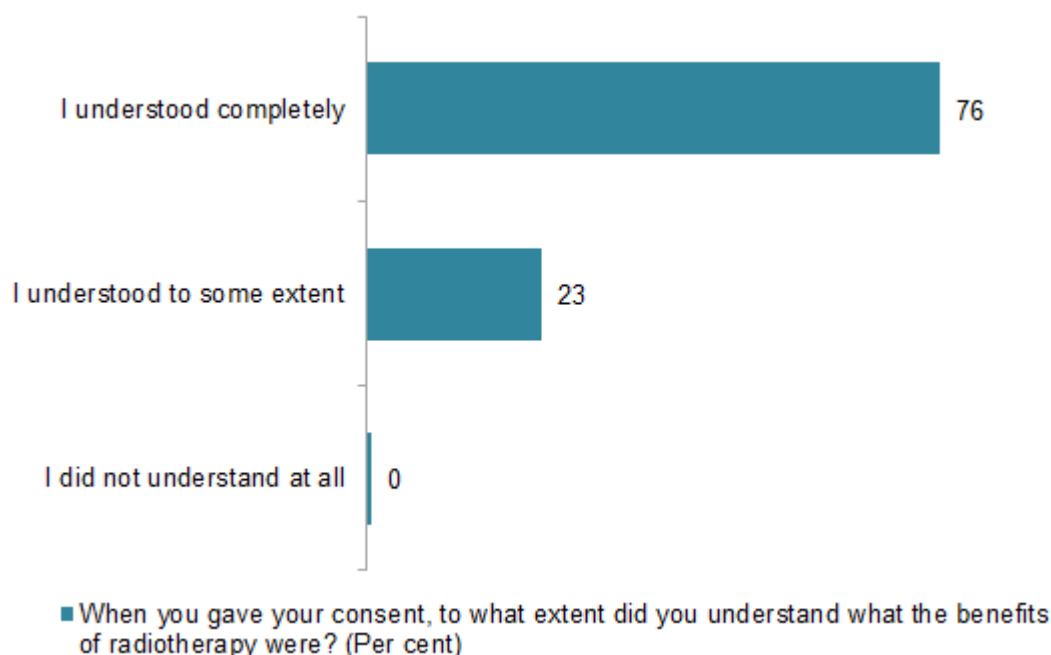
3.3 In general responses were mixed. Patients were most positive about being given the opportunity to ask questions and being treated with dignity and respect as well as confidence in the staff taking consent. For example:

- 98% of patients indicated that they were given the opportunity to ask questions before giving consent.
- 96% of patients said that they were treated with dignity and respect.
- 93% of patients said that they had confidence in the doctor or other health professional who took their consent.

3.4 However patients were markedly less positive about understanding both the benefits and the side-effects of radiotherapy as well as responses to their questions:

- 65% of patients indicated they understood 'completely' the side-effects, while one-third (33%) indicated that they understood 'to some extent'.
- 76% of patients indicated they understood 'completely' the benefits of radiotherapy, while around one in five (23%) only understood 'to some extent' (Chart 4).
- 85% of patients said that they were satisfied with the answers they received to questions that they asked, while around one in six (15%) said that they were only satisfied 'to some extent'.

Chart 4 Understanding the benefits of radiotherapy (%)



Variation between centres

3.5 Across the five radiotherapy centre, there was very little variation in the experiences of patients around consent.

4 RESULTS – INFORMATION BEFORE RADIOTHERAPY TREATMENT

Summary

4.1 Scores were generally high across most of the questions in this section but there were some which gave a more mixed picture. Of those who do receive information, most are happy with what they get. There are still some patients who don't receive the information they need however. Most patients (77%) were invited to the radiotherapy department before they started treatment, and virtually all of these (98%) found this helpful. But some patients said that they didn't get any written information before their radiotherapy treatment (14%), and/or that it wasn't of the right quality to help with their treatment.

Detailed results

4.2 The questions on information before treatment asked included: the information they were given and whether this was easy to understand; whether they had been able to visit the radiotherapy department prior to treatment starting; and whether they were given more broad information on local support services. The results are summarised in table 2.

Table 2 Summary of the results to questions about information before radiotherapy treatment

Measure	Negative	Neutral	Partly Positive	Positive
Given/sent written information by a member of staff	14	n/a	n/a	86
Information/arrangements for first appointment easy to understand	1	9	n/a	90
Told about local cancer information and support service	27	n/a	n/a	73
Overall amount of information given before starting radiotherapy	2	n/a	43	55
Invited to Radiotherapy department to be given information/explanation before starting treatment	23	n/a	n/a	77
Found information/explanation given helpful	2	n/a	n/a	98

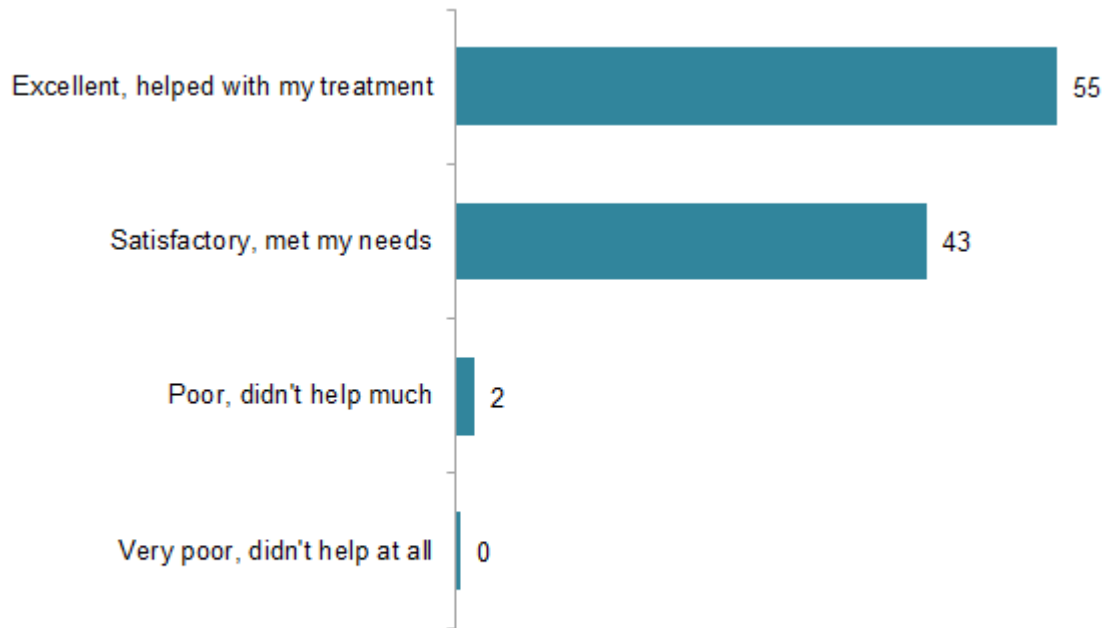
Note: percentages may not add up to 100% due to rounding

- 4.3 In general the responses were mixed. Of those people who do receive information, most find it helpful and easy to understand. For example:
- 90% of patients said that the information/arrangements for their first radiotherapy visit was easy to understand.
 - 55% of patients said that the information given to them before they started treatment was excellent, and helped with their treatment. Another 43% said that it was satisfactory, and met their needs. (chart 5)
 - 77% of patients said that they were invited to visit the radiotherapy department before they started treatment, to be given information and an explanation about radiotherapy. The vast majority of these (98%) said that it was helpful.
- 4.4 However, there were some patients who said they didn't receive the information they required and if they did, some found that it wasn't easy to understand. For example:
- 14% of patients said that they didn't get any written information before they started their radiotherapy treatment, and a further 5% couldn't remember if they been sent or given any
 - Of those who did receive information, 9% said that it was only easy to understand to some extent, and small number (1%) said that it wasn't easy to understand at all.
 - Almost one-third (27%) said that they didn't get any information about the local cancer and information support services; and a large number (12%) said that they didn't know/couldn't remember this.
 - A small number (2%) said that the amount of information given to them before starting radiotherapy was poor, and didn't help much; 5 patients said that it was very poor, and didn't help at all; and 1% said that they were not given any information before their radiotherapy started.
 - Over in in five (23%) patients said that they weren't invited to visit the radiotherapy department before their treatment started. Most of these (61%) said that it would have been helpful; a smaller number (39%) said that it wouldn't have been helpful.

Variation between centres

- 4.5 In the main there was little variation between the five radiotherapy centres. The exception to this was on the following questions:
- Information before radiotherapy – scores ranged from 74% to 94% positive, with Dundee Cancer Centre doing particularly well.
 - Told about local cancer and information support service – scores ranged from 66% to 88% positive, with Department of Clinical Oncology (Inverness) doing particularly well.

Chart 5 Overall amount of information given before starting radiotherapy (%)



■ Overall was the amount of information given to you before you started your radiotherapy: (Per cent)

5 RESULTS – WEBSITE INFORMATION

Summary

5.1 While only a minority of patients (16%) looked for information about radiotherapy on hospital websites, the vast majority of those who did find it very helpful (69%) or fairly helpful (30%). Of those patients who didn't look for information on hospital websites, a large proportion (26%) said that they didn't have internet access; and 19% said that they didn't know there was information there.

Detailed results

5.2 Most of the questions in this section were information questions, so they were intended to find out about how many people accessed information on line and if not, their reasons for not doing so. While numbers using the website for information purposes were relatively low, most of these found the information helpful, as shown in table 3 below.

Table 3 Summary of the results to questions about website information

Measure	Negative	Neutral	Partly Positive	Positive
Found hospital website information helpful	1	n/a	30	69

Note: percentages may not add up to 100% due to rounding

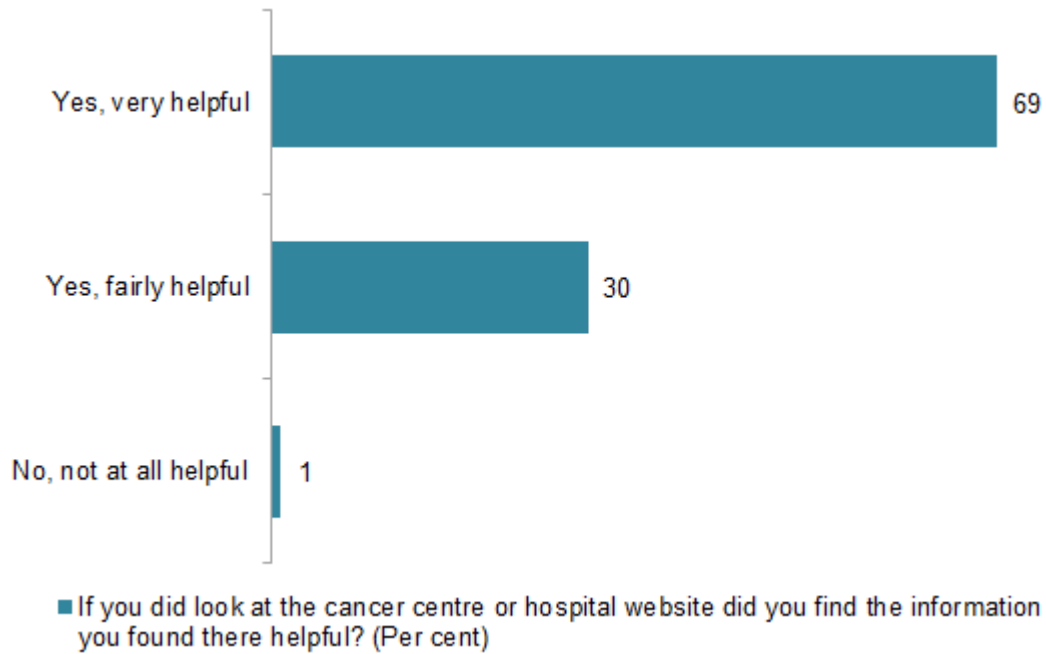
5.3 Responses were generally positive:

- Of those who did look for information about radiotherapy on the cancer centre or hospital website, 69% said that it was very helpful, and 30% said that it was fairly helpful (chart 6).

5.4 When asked why patients didn't look on the hospital website for information there was a mix of reasons:

- Of those patients who didn't look for information on hospital websites, a large proportion (26%) said that they didn't have internet access; 19% said that they didn't know there was information there; 32% said that they didn't need to access information; and 18% said that they didn't want to. 5% of patients said that there was some other reason.

Chart 6 Information on the hospital website helpful (%)



Variation between centres

5.5 In the main there was little variation between the five radiotherapy centres. The exception was on the question about information on hospital website:

- Information on the hospital website helpful – scores ranged from 89% to 100% positive with Aberdeen Radiotherapy Centre, Dundee Cancer Centre and Edinburgh Cancer Centre scoring particularly well.

6 RESULTS – ABOUT YOUR RADIOTHERAPY

Summary

6.1 Again, there were some mixed results when patients were asked about their radiotherapy, but for the most part patients were very positive. 97% of patients who wanted someone to talk to in hospital about their worries and fears said that they were able to find someone. The vast majority of patients (97%) said that they were told very clearly how many fractions they would need. But some patients said that they weren't given a very clear explanation of their plan of treatment (10%); or weren't given very clear information to help manage their side-effects (27%).

Detailed results

6.2 Patients were asked a series of questions about radiotherapy including: whether they were told how many treatments were needed; how long the course of treatment would last; whether they were told about the possible side-effects; and if they were able to talk to someone about their worries and fears. A summary of the results is in table 4 below:

Table 4 Summary of the results to questions about radiotherapy

Measure	Negative	Neutral	Partly Positive	Positive
Told how many radiotherapy treatments probably needed	0	3	n/a	97
Told how long in total course of radiotherapy treatment would last	1	4	n/a	96
Plan of treatment clearly explained by a member of staff	2	9	n/a	90
Given information to help manage side-effects of treatment	4	23	n/a	73
Information given by radiographer at treatment visit the same as that given by doctor/radiographer at clinic visit	1	12	n/a	87
Someone in the hospital to talk to about worries or fears	3	n/a	n/a	97

Note: percentages may not add up to 100% due to rounding

6.3 There were some positive responses to these questions with patients largely reporting that they had been given clear information on most aspects of their radiotherapy treatment, for example:

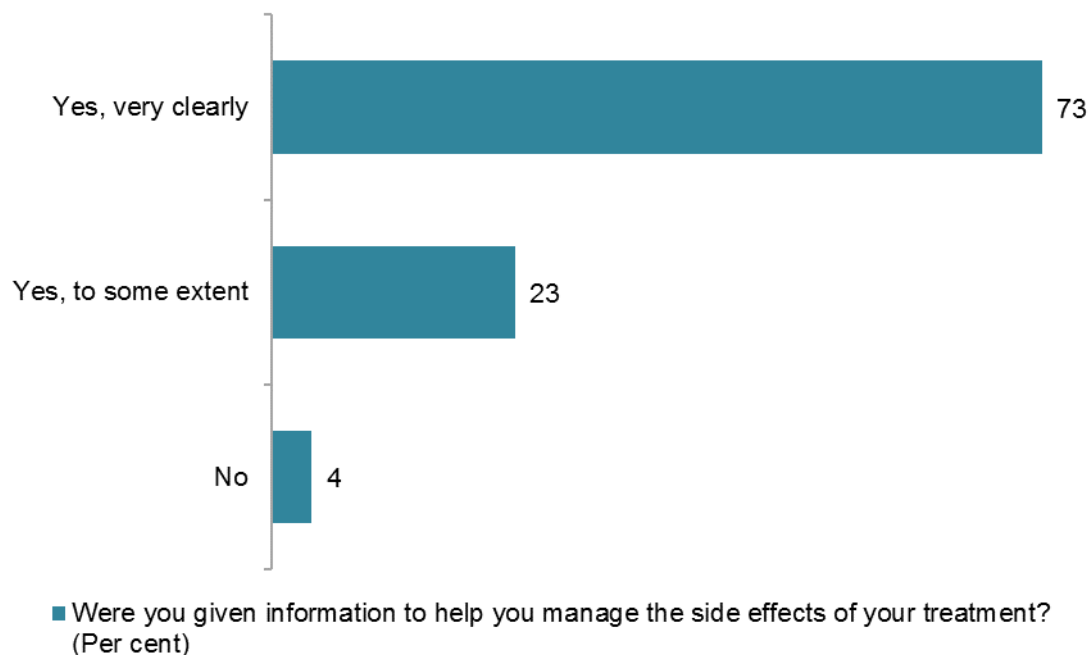
- The vast majority of patients (97%) said that they were told very clearly how many fractions they would need.
- And again, the vast majority of patients (96%) said that they were told very clearly how long in total their course of radiotherapy treatment would last.

- Most patients (90%) said that their plan of treatment was explained to them very clearly.
- 87% of patients said that they were given exactly the same information at their treatment visit as they were at their clinic visit.
- Of those patients who wanted to talk to someone in the hospital about their worries and fears, 97% said that they found someone. 73% said that these were in the radiotherapy department; 24% said that they were elsewhere.

6.4 There were some aspects of radiotherapy which could be improved, for example:

- 9% of patients said that their treatment plan was only explained to some extent; and a small number (2%) said that it wasn't explained at all.
- Nearly three-quarters (73%) of patients said that they were given clear information to help them manage the side-effects of their treatment. But 23% said that this was only true to some extent; and a small number (4%) said that they weren't given such information (chart 7).

Chart 7 Given information to help manage side effects of treatment (%)



Variation between centres

6.5 In the main there was little variation between the five radiotherapy centres. The exception to this was on the following questions:

- Explaining plan of treatment – scores ranged from 87% to 95% positive, with Dundee Cancer Centre doing particularly well.
- Information about managing side effects – scores ranged from 68% to 79% positive, with Dundee Cancer Centre doing particularly well.

- Consistency of information – scores ranged from 85% to 93% positive, with Dundee Cancer Centre doing particularly well.

7 RESULTS – DAILY TREATMENT VISITS

Summary

7.1 There were mixed results in this section, however, virtually 100% of patients said that the environment of the radiotherapy department (the waiting room, the treatment room, and the department as a whole) was “good” or “very good”. There were some logistical issues, where scores were lower (with car parking, being informed of delays, and changing facilities). There is room for improvement on a number of questions to do with communication. The majority of patients are having formal reviews of their treatment, but there are large numbers (26%) where this is not the case.

Detailed results

7.2 These questions asked about getting to and from appointments and the environment when patients arrived. This included: whether or not parking was easy; appointments started on time; whether the department was clean; how the general environment was rated by patients; and whether or not they were able to communicate adequately with radiographers. A summary of the responses is in table 5 below:

Table 5 Summary of the results to questions about daily treatment visits

Measure	Negative	Neutral	Partly Positive	Positive
Easy to park if patient travelled by car	44	n/a	n/a	56
How soon after appointment time radiotherapy started	1	14	n/a	85
Informed of any delays	10	21	n/a	69
Rating of environment in the waiting room	1	n/a	28	71
Rating of environment in the treatment room	0	n/a	15	85
Rating of environment in the department as a whole	0	n/a	13	87
Changing facilities allowed patient to maintain their dignity	4	19	n/a	77
Told could communicate with the radiographers outside the room during treatment	27	n/a	n/a	73
Staff took adequate care when helping patient into right position for treatment	0	3	n/a	97
Had opportunity to discuss any questions with radiographer	2	14	n/a	85
Had regular formal review of treatment	26	n/a	n/a	74

Note: percentages may not add up to 100% due to rounding

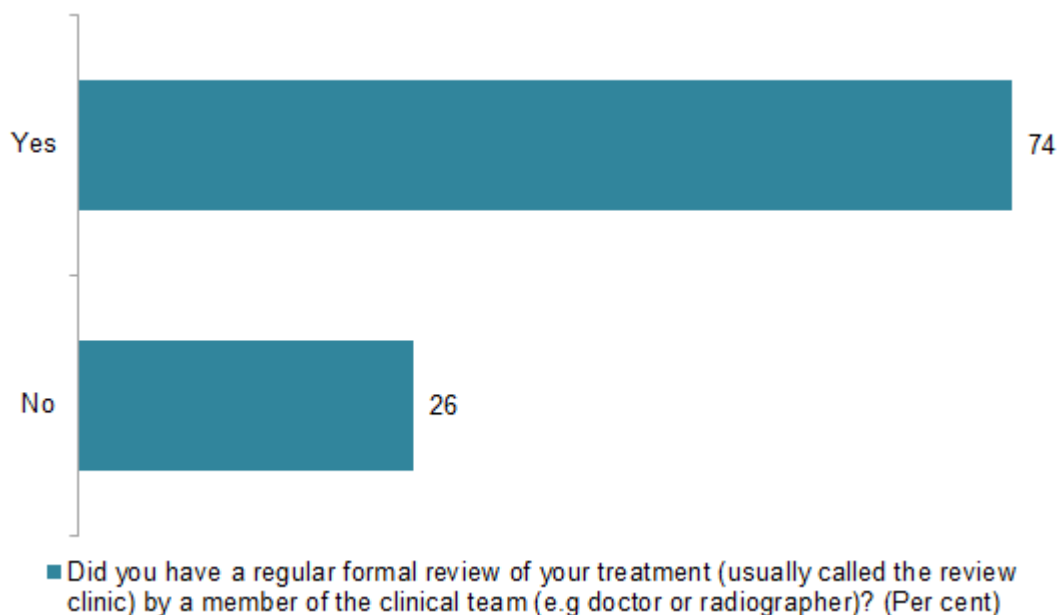
7.3 There were mixed results in many of these questions however the most positive results were:

- 71% of patients said that the environment of the waiting room was “very good”, and another 28% said that it was “good”. Only 18 patients (1%) said that it was “poor”, and none said that it was “very poor”.
- 85% of patients said that the environment of the treatment room was “very good”, and another 15% said that it was “good”. Only 3 patients said that it was “poor”, and none said that it was “very poor”.
- 87% of patients said that the environment of the department as a whole was “very good”, and another 13% said that it was “good”. Only 2 patients said that it was “poor”, and none said that it was “very poor”.
- Virtually all patients said that staff took adequate care whilst helping get them into the right position for treatment. 97% said that this was definitely the case; and 3% said that it was the case to some extent. Only 2 patients said that it wasn’t the case.

7.4 There were other areas which patients reported more difficulty or dissatisfaction, particularly on the questions around logistics of getting to appointments and some of the communication issues. For example:

- Of those who needed to park, 44% said that it was not easy.
- While most patients (85%) said that their treatment started on time or within 20 minutes of their appointment, some patients (14%) said that it started between 20 minutes and 1 hour of their appointment time; and a small number (10 patients, 1%) said that it started more than 1 hour after their appointment time. Nearly one in ten patients (9%) said that it varied from visit to visit.
- If appointments were delayed, nearly a third of patients said that they were never or rarely (10%) or only sometimes (21%) informed of any delays.
- While just over three-quarters of patients said that changing facilities allowed them to maintain their dignity, nearly one-fifth (19%) said that this was only the case to some extent and 4% said not at all.
- A number of patients (27%) said that they weren’t told they could communicate with the radiographers during appointments; and a further 11% said that they didn’t know/couldn’t remember if they had been told.
- While most (85%) of patients agreed completely that they had an opportunity to discuss questions with their radiographer, there were some patients (2%) who said that they didn’t; and a further 14% only agreed with this to some extent.
- Just over one-quarter (26%) of patients said that they didn’t have a regular formal review of treatment (chart 8).

Chart 8 Regular formal reviews (%)



Variation between centres

7.5 In the main there was little variation between the five radiotherapy centres. The exception to this was on the following questions:

- Parking – scores ranged from 28% to 91% positive, with Edinburgh Cancer Centre doing particularly well.
- Changing facilities – scores ranged from 68% to 97% positive with Dundee Cancer Centre doing particularly well.
- Regular formal review – scores ranged from 61% to 92% positive with Department of Clinical Oncology (Inverness) doing particularly well.
- Delays – scores ranged from 59% to 82% positive with Dundee Cancer Centre doing particularly well.
- Communicating with radiographers – scores ranged from 68% to 90% positive, with Dundee Cancer Centre doing particularly well.
- Appointment time – scores ranged from 81% to 97%, with Dundee Cancer Centre doing particularly well.
- Discussing questions with radiographer – scores ranged from 83% to 90% positive with Dundee Cancer Centre doing particularly well.

8 RESULTS – INFORMATION ABOUT SUPPORT

Summary

8.1 Of those patients who said they would have liked information about support or self-help groups, 17% said that they didn't get it. Of those patients who did get information, the biggest proportion (39%) were given information about general cancer support groups in their area.

Detailed results

8.2 This section looked at the support information patients were given and whether or not it was helpful. This included whether or not people were given this information and if they wanted it; and what type of information was given.

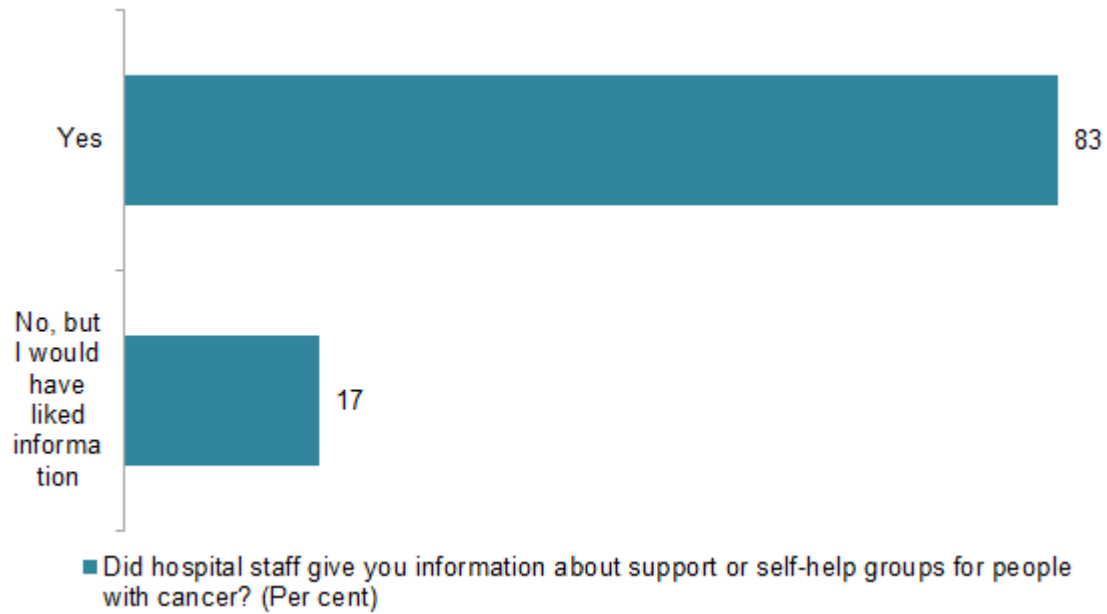
Table 6 Summary of the results to questions about support information

Measure	Negative	Neutral	Partly Positive	Positive
Hospital staff gave information about support or self-help groups for people with cancer	17	n/a	n/a	83

Note: percentages may not add up to 100% due to rounding

- 8.3 Most people answered positively:
- Of those patients who said they would have liked information about support or self-help groups, 83% said that they got it, and 17% that they didn't (chart 9). 13% of patients said that they wouldn't have wanted this information; 21% said that it wasn't necessary as they already had this information.
 - 39% of patients who said they were given such information were given information about general support groups in their area. Smaller numbers were given information about other types of groups: 14% said they were given information about support groups for their specific type of cancer in their area; 14% said they were given information about national charities; 6% said that they were given information about other groups.

Chart 9 Information about support or self-help groups (%)



Variation between centres

8.4 There was considerable variation in the scores for information about support or self-help groups. Scores ranged from 78% to 92% positive, with Department of Clinical Oncology (Inverness) doing particularly well.

9 RESULTS – FOLLOWING TREATMENT

Summary

9.1 Whilst many patients said that they were given a range of information and advice following treatment, there are significant numbers of patients for whom this needs to be improved. Most patients said that they were given a number to call to see if they had any problems following treatment, but a proportion (13%) said that they weren't. 15% of patients said that they didn't know what the arrangements were for their next visit. And 44% of patients said that they were not given written information about what to expect in the weeks following treatment.

Detailed results

9.2 This section asked patients about what happened after their treatment had finished. Questions included: whether or not they were given a number to call if they had any concerns; if they knew the arrangements for their next visit; and whether or not they were given written information on what to expect following their treatment. The results are summarised in table 7 below:

Table 7 Summary of the results to questions about following treatment

Measure	Negative	Neutral	Partly Positive	Positive
Patient given a number to call if any problems in relation to their radiotherapy	13	n/a	n/a	87
Patient knows arrangements for next visit	15	n/a	n/a	85
Given written information about what to expect in the few weeks following treatment and post treatment care	44	n/a	n/a	56

Note: percentages may not add up to 100% due to rounding

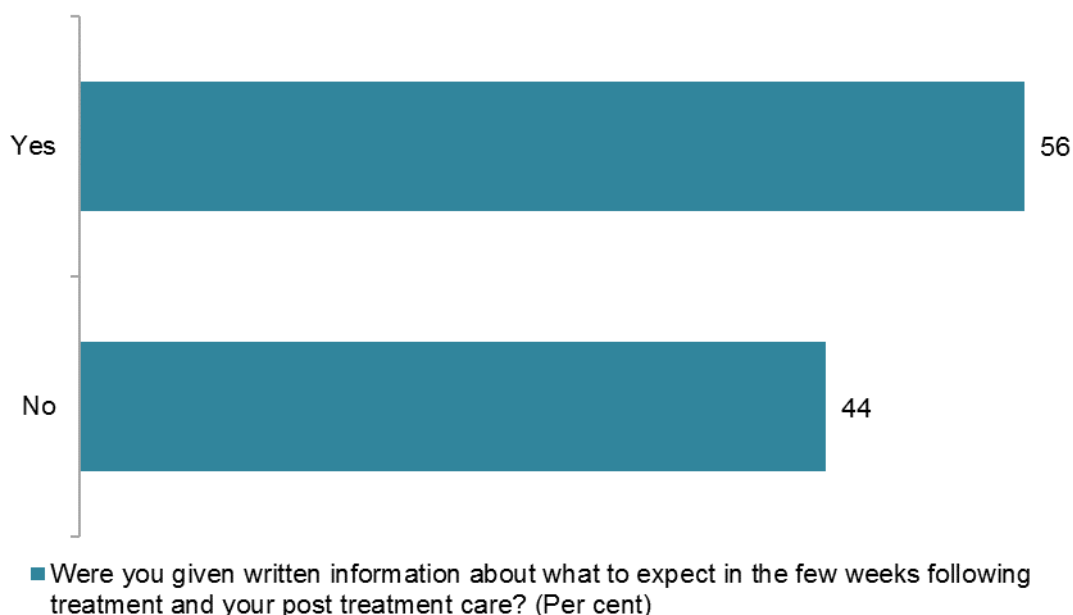
9.3 There were some positive results here, for example:

- 87% of patients said that they were given a number to call if they had any problems in relation to their radiotherapy. There were a number of patients who weren't given the number however (13%)
- 85% of patients said that they knew the arrangements for their next visit. However again, a number (15%) said that they didn't know this.

9.4 Patients were less positive about written information on finishing their treatment:

- Only 56% said that they were given written information about what to expect in the few weeks following treatment and their post treatment care. A significant number (44%) said that they weren't; and 3% said that they couldn't remember (chart 10).

Chart 10 Information about what to expect in the few weeks following treatment and post treatment care (%)



Variation between centres

9.5 Across the five radiotherapy centres, there was some variation on questions about information and advice following treatment:

- Information about what to expect in the few weeks following treatment and post treatment care – scores ranged from 37% to 94% positive, with Dundee Cancer Centre doing particularly well.
- Given a number to call if any problems – scores ranged from 63% to 100% positive, with Dundee Cancer Centre doing particularly well.
- Arrangements for next visit – scores ranged from 82% to 91% positive, with Dundee Cancer Centre doing particularly well.

10 RESULTS – YOUR OVERALL RADIOTHERAPY CARE

Summary

- 10.1 97% of patients rated their overall care as excellent or very good, with 82% giving the highest possible score.
- 10.2 Scores on questions about staff were particularly strong: 91% of patients said that staff always took account of what mattered to them (and another 8% said that this was sometimes the case); and 97% of patients said that staff always treated them with compassion and understanding (and another 3% said that this was sometimes the case).
- 10.3 But there is room for improvement in other scores. 4% of patients said that they weren't involved as much as they wanted to be in decisions about their treatment and care; and another 21% said that they were only involved to some extent. 1% of patients said that the amount of information given at the start of their radiotherapy was poor; and another 36% said that it was only satisfactory.

Detailed results

- 10.4 These last questions concentrated on patients' overall ratings of care and treatment. Specifically they were asked about information they received at the start of treatment and their rating of the amount of information received; whether they felt involved in decisions about care and treatment; how staff treated them; and then, their overall rating of their care. The results are summarised in table 8 below:

Table 8 Summary of the results to questions about overall radiotherapy care

Measure	Negative	Neutral	Partly Positive	Positive
Given information at the start of radiotherapy	1	n/a	n/a	99
Overall rating of amount of information given at the start of radiotherapy	1	n/a	36	62
Patient involved as much as wanted to be in decisions about care and treatment	4	21	n/a	74
Patient felt that staff took account of what mattered to them	1	8	n/a	91
Patient felt that staff treated them with compassion and understanding during treatment	0	3	n/a	97
Overall rating of care	0	0	2	97

Note: percentages may not add up to 100% due to rounding

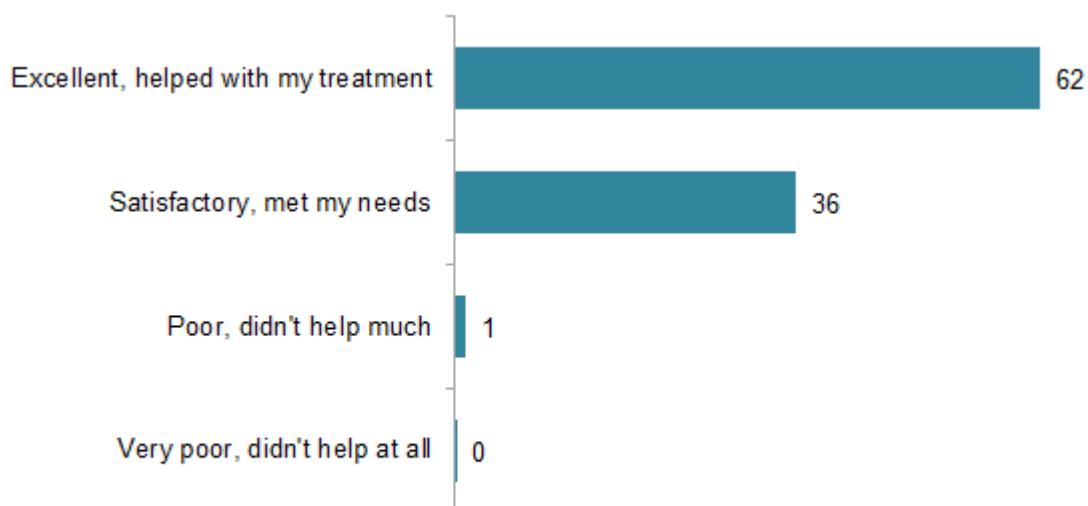
10.5 Patients were generally very positive about their overall radiotherapy care and staff, for example:

- 99% of patients said that the amount of information given to them at the start of their radiotherapy was satisfactory or excellent (chart 11).
- 95% of patients said that they were involved as much as they wanted to be (definitely or to some extent) in decisions about their care and treatment
- 99% of patients said that staff took account of what mattered to them, with 91% saying that this was always the case (and the other 8% saying that it was sometimes the case).
- Every patient said that staff treated them with compassion and understanding during their treatment, with 97% saying that this was always the case (and the other 3% saying that it was sometimes the case).
- 97% of patients rated their overall care as excellent or very good, with 82% giving the highest possible score. Another 2% said that their care was good (chart 12).

10.6 There were a small number of areas where patients were less positive, for example:

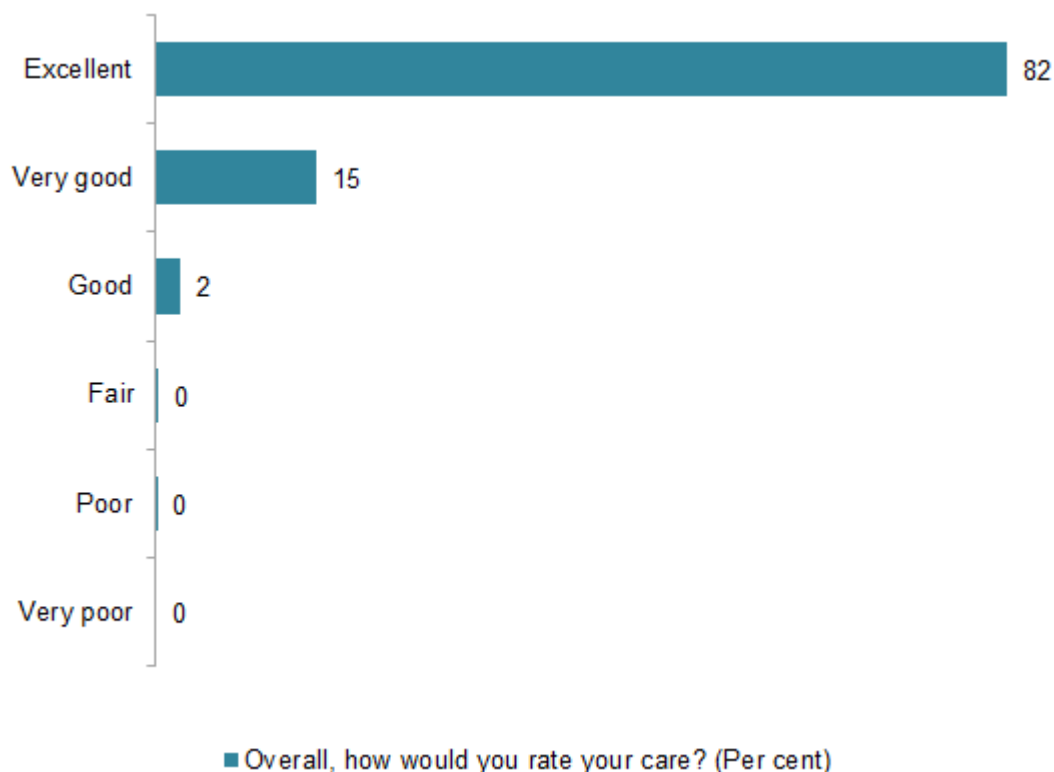
- While patients received information before their treatment started, only 62% said that it was excellent and helped with their treatment, with 36% saying that it was satisfactory and met their needs.
- When asked about whether patients felt involved in decisions on their treatment and care around one-fifth of patients, (21%) said that they were only involved as much as they wanted to be to some extent; 4% of patients said that they weren't involved as much as they would have liked to have been and another 3% said that they did not wish to be involved.

Chart 11 Overall amount of information given at start of radiotherapy (%)



■ Overall was the amount of information given to you at the start of your radiotherapy: (Per cent)

Chart 12 Overall rating of care (%)



Variation between centres

10.7 Across the five radiotherapy centres, there was very little variation on the overall rating of radiotherapy care, however there was some variation on person centred questions relating to involvement in decisions and taking account of what matters to patients:

- Involvement in decisions – scores ranged from 72% to 79% positive, with Dundee Cancer Centre doing particularly well.
- Staff taking account of what matters to patients – scores ranged from 88% to 95% positive, with Department of Clinical Oncology (Inverness) doing particularly well.

11 RESULTS – COMPARISON OF RESULTS WITH THE ENGLISH RADIOTHERAPY SURVEY 2012

- 11.1 The vast majority of the questions used in the survey had previously been used in a Radiotherapy Patient Survey in England in 2012. This section provides a high level summary of these comparisons in the areas where they are observed. A full set of comparisons is presented in tables in [Appendix A](#) to this report. Comparisons have only been made where questions were the same or very similarly worded in both questionnaires.
- 11.2 Any comparisons should be viewed in a broad context rather than around specific questions as there are differences in the way the surveys were administered (posted in England while in Scotland postal return after handing out at the end of radiotherapy treatment). In addition there are important differences between the organisation and monitoring of radiotherapy care in Scotland and England. That said, the requirement for the provision of safe, effective and person centred care and indicators of quality of care are the same.

Overall summary

- 11.3 Comparisons of the Scottish survey with the English results have found more similarities than differences between patients' experiences of radiotherapy care. Both report that patients are in the main positive about their radiotherapy care and treatment.
- 11.4 Where Scottish patients are more positive than English patients is around the environment of the radiotherapy department, and the overall experience of radiotherapy care: 97% of patients in Scotland compared to 83% in England rated their overall care as excellent or very good.
- 11.5 A number of areas where Scottish patients are less positive than English patients is around written information: 14% of patients in Scotland said that they didn't get any written information before their treatment (compared to only 6% in England); and only 56% of patients in Scotland said that they were given written information about what to expect in the few weeks following treatment and their post treatment care (compared to 77% in England).

Consent

- 11.6 Scores on consent are broadly similar to the same questions asked in the English Radiotherapy Survey.
- 11.7 85% of patients said that they were completely satisfied with the answers they received to questions that they asked (compared to 82% in England); and 93% of patients said that they had complete confidence in the doctor or other health professional who took their consent (compared to 91% in England). Exactly the same percentage of patients (96%) of patients in both countries said that they were definitely treated with dignity and respect.

Information before radiotherapy treatment

- 11.8 Compared to the same questions in the English Radiotherapy Survey, scores on questions about information before radiotherapy treatment are better in some cases and worse in others.
- 11.9 Patients in England tended to be slightly more positive (78%) than those in Scotland (73%) who said that they were told about the local cancer and information support service at the hospital. Slightly more patients in Scotland (90%) than in England (89%) said that the information/arrangements for their first radiotherapy visit was easy to understand. And slightly more patients in Scotland (55%) than in England (54%) said that the information given to them before they started treatment was excellent, and helped with their treatment.
- 11.10 But more patients in Scotland (14%) than in England (6%) said that they didn't get any written information before their treatment.

Website information

- 11.11 Far fewer patients in Scotland (16%) than in England (21%) looked for information about radiotherapy on hospital websites. But of those who did, more found it very helpful in Scotland (69%) than in England (56%).

About your radiotherapy

- 11.12 All of the scores in this section were very similar to those in the English Radiotherapy Survey. Interestingly, there were fewer radiotherapy inpatients (only 3%) in the English Radiotherapy Survey than in Scotland (11%).

Daily treatment visits

- 11.13 Compared to the same questions in the English Radiotherapy Survey, scores on questions about daily treatment visits are better in some cases and worse in others.
- 11.14 More patients in Scotland (71%, 85%, 87%) than in England (54%, 69%, 67%) said that the environment of the radiotherapy department (the waiting room, the treatment room, and the department as a whole) was "very good". And more patients in Scotland (85%) than in England (67%) said that their treatment started on time or within 20 minutes of their appointment.
- 11.15 But of those patients who needed to park, more in Scotland (44%) than in England (32%) said that it was not easy to park. And fewer patients in Scotland (77%) than in England (83%) said that the changing facilities allowed them to maintain their dignity.
- 11.16 Interestingly, more patients in Scotland (25%) than in England (20%) said that they had only 1-5 fractions during their last course of radiotherapy.

Following treatment

11.17 On two of the questions in this section, patients in Scotland were less positive than patients in England.

11.18 Fewer patients in Scotland (85%) than in England (92%) said that they knew the arrangements for their next visit. And fewer patients in Scotland (56%) than in England (77%) said that they were given written information about what to expect in the few weeks following treatment and their post treatment care.

12 APPENDIX A: COMPARISON OF RESULTS WITH THE ENGLISH RADIOTHERAPY SURVEY 2012

The following tables provide comparable figures from the Scottish and English radiotherapy patient experience surveys.

Table A: Description of survey respondents

Question: What year were you born?		
	Scotland	England
16 - 34	1%	1%
35 - 64	37%	38%
Over 65	62%	61%
Question: Are you male or female?		
	Scotland	England
Male	43%	44%
Female	57%	56%

Table B: Consent

Question: Were you given the opportunity to ask questions before giving consent?		
	Scotland	England
Yes	98%	99%
No	2%	1%
Question: If you did ask questions, were you satisfied with the answers that you received?		
	Scotland	England
Yes, completely	85%	82%
Yes, to some extent	15%	18%
No	0%	0%
Question: Did you have confidence in the doctor or other health professional who took your consent for your radiotherapy?		
	Scotland	England
Yes, completely	93%	91%
Yes, to some extent	7%	8%
No	1%	0%
Question: Were you treated with dignity and respect by the doctor or other health professional who took your consent for your radiotherapy?		
	Scotland	England
Yes, definitely	96%	96%
Yes, to some extent	3%	3%
No	0%	0%

Table C: Information Before Radiotherapy Treatment

Question: Were you given or sent any written information about radiotherapy by a member of staff (e.g. doctor, radiographer or nurse specialist) before your radiotherapy?		
	Scotland	England
Yes	86%	94%
No	14%	6%
Question: Was the information/arrangements for your first appointment at the radiotherapy department easy to understand?		
	Scotland	England
Yes, completely	90%	89%
Yes, to some extent	9%	10%
No	1%	1%
Question: Were you told about the local cancer information and support service at the hospital (sometimes called cancer information centre)?		
	Scotland	England
Yes	73%	78%
No	27%	22%
Question: Overall was the amount of information given to you before you started your radiotherapy:		
	Scotland	England
Excellent, helped with my treatment	55%	53%
Satisfactory, met my needs	43%	44%
Poor, didn't help much	2%	2%
Very poor, didn't help at all	0%	0%
Question: Were you invited to the Radiotherapy department before you started treatment to be given information and an explanation about radiotherapy (pre-treatment or planning)?		
	Scotland	England
Yes	77%	84%
No	23%	16%
Question: If invited to the Radiotherapy department did you find it helpful?		
	Scotland	England
Yes	98%	98%
No	2%	2%

Table D: Website Information

Question: Did you look for information about radiotherapy on the cancer centre or hospital website where you had your radiotherapy?		
	Scotland	England
Yes	16%	21%
No	84%	79%
Question: If you did look at the cancer centre or hospital website did you find the information you found there helpful?		
	Scotland	England
Yes, very helpful	69%	56%
Yes, fairly helpful	30%	41%
No, not at all helpful	1%	1%
I did not find any information about radiotherapy on the website	0%	1%
Question: If you did not look at the cancer centre or hospital website, was this because:		
	Scotland	England
Didn't need to	32%	40%
Didn't want to	18%	22%
Didn't know there was any information on the website	19%	29%
No internet access*	26%	-
Some other reason	5%	10%

* The English survey did not have this option in their questionnaire.

Table E: About Your Radiotherapy

Question: Did you have the majority of your radiotherapy as an inpatient or as an outpatient?		
	Scotland	England
I had the majority of my radiotherapy as an inpatient	11%	3%
I had the majority of my radiotherapy as an outpatient	89%	97%
Question: Were you told how many radiotherapy treatments (sometimes called visits or fractions) you would probably need?		
	Scotland	England
Yes, very clearly	97%	96%
Yes, to some extent	3%	3%
No	0%	1%
Question: Were you told how long in total your course of radiotherapy treatment would last?		
	Scotland	England
Yes, very clearly	96%	94%
Yes, to some extent	4%	4%
No	1%	1%
Question: Was your plan of treatment explained clearly to you by a member of staff?		
	Scotland	England
Yes, very clearly	90%	90%
Yes, to some extent	9%	9%
No	2%	1%
Question: Were you given information to help you manage the side effects of your treatment?		
	Scotland	England
Yes, very clearly	73%	72%
Yes, to some extent	23%	23%
No	4%	5%
Question: Was the information given to you by your radiographer at the treatment visit the same as you were told by the doctor/radiographer at your clinic visit?		
	Scotland	England
Yes, exactly the same	87%	91%
It was a little different	12%	9%
No, it was completely different	1%	1%

Table F: Daily Treatment Visits

Question: How did you usually get to the hospital where you had your radiotherapy?		
	Scotland	England
By car	74%	72%
By public transport (bus, train, taxi)	12%	13%
By ambulance / hospital transport	12%	13%
I walked / cycled	2%	1%
Question: If you travelled by car, was it easy to park?		
	Scotland	England
Yes	56%	68%
No	44%	32%
Question: How soon after your appointment time did your radiotherapy usually start?		
	Scotland	England
On time or within 20 minutes of my appointment	85%	77%
Between 20 minutes and 1 hour of my appointment time	14%	21%
More than 1 hour after my appointment time	1%	2%
Question: Were you informed of any delays?		
	Scotland	England
Yes, always	69%	73%
Yes, sometimes	21%	23%
Never or rarely	10%	4%
Question: What was the environment of the radiotherapy department like in respect of the waiting room?		
	Scotland	England
Very good	71%	54%
Good	28%	43%
Poor	1%	3%
Very poor	0%	0%
Question: What was the environment of the radiotherapy department like in respect of the treatment room?		
	Scotland	England
Very good	85%	69%
Good	15%	30%
Poor	0%	1%
Very poor	0%	0%
Question: What was the environment of the radiotherapy department like in respect of the department as a whole?		
	Scotland	England
Very good	87%	67%
Good	13%	32%
Poor	0%	1%
Very poor	0%	0%

Table F: Daily Treatment Visits (continued)

Question: Did you feel the changing facilities allowed you to maintain your dignity?		
	Scotland	England
Yes	77%	83%
Yes, to some extent	19%	14%
No	4%	3%
Question: If you had any questions about the radiotherapy, did you have the opportunity to discuss these with the radiographer?		
	Scotland	England
Yes, completely	85%	81%
Yes, to some extent	14%	17%
No	2%	2%
Question: During your last course of radiotherapy, how many treatments (sometimes called visits or fractions) did you have?		
	Scotland	England
1 - 5	25%	19%
5 - 10	7%	9%
More than 10	65%	67%
Don't know / Can't remember	3%	4%
Question: Did you have a regular formal review of your treatment (usually called the review clinic) by a member of the clinical team (e.g. doctor or radiographer)?		
	Scotland	England
Yes	74%	81%
No	26%	19%

Table G: Information About Support

Question: Did hospital staff give you information about support or self-help groups for people with cancer?		
	Scotland	England
Yes	83%	85%
No, but I would have liked information	17%	15%
Question: If yes, what type of groups were you given information about?		
	Scotland	England
General cancer support groups in my area	39%	68%
Support groups for my specific type of cancer in my area	14%	34%
National cancer charities	14%	35%
Other groups	6%	9%

Table H: Following Treatment

Question: Have you been given a number to call if you have any problems in relation to your radiotherapy?		
	Scotland	England
Yes	87%	87%
No	13%	13%
Question: Do you know what the arrangements are for your next visit to see your consultant or other member of staff?		
	Scotland	England
Yes	85%	92%
No	15%	8%
Question: Were you given written information about what to expect in the few weeks following treatment and your post treatment care?		
	Scotland	England
Yes	56%	77%
No	44%	23%
Question: Were you given information at the start of radiotherapy?		
	Scotland	England
Yes	99%	99%
No	1%	1%
Question: Overall was the amount of information given to you at the start of your radiotherapy:		
	Scotland	England
Excellent, helped with my treatment	62%	54%
Satisfactory, met my needs	36%	44%
Poor, didn't help much	1%	2%
Very poor, didn't help at all	0%	0%
Question: Overall, how would you rate your care?		
	Scotland	England
Excellent	82%	69%
Very good	15%	24%
Good	2%	5%
Fair	0%	1%
Poor	0%	0%
Very poor	0%	0%

13 APPENDIX B: PER CENT POSITIVE EXPLANATION

The table below shows which answers were classed as positive, partly positive, neutral and negative for each question.

Q	Question text	All Positive percent	Partly Positive percent	Neutral percent	Negative percent
1.	When you gave your consent, to what extent did you understand what the benefits of radiotherapy were?	I understood completely		I understood to some extent	I did not understand at all
2.	When you gave your consent, to what extent did you understand what the side- effects of radiotherapy were?	I understood completely		I understood to some extent	I did not understand at all
3.	Were you given the opportunity to ask questions before giving consent?	Yes			No
4.	If you did ask questions, were you satisfied with the answers that you received?	Yes, completely		Yes, to some extent	No
5.	Did you have confidence in the doctor or other health professional who took your consent for your radiotherapy?	Yes, completely		Yes, to some extent	No
6.	Were you treated with dignity and respect by the doctor or other health professional who took your consent for your radiotherapy?	Yes, definitely		Yes, to some extent	No

Q	Question text	All Positive percent	Partly Positive percent	Neutral percent	Negative percent
7.	Were you given or sent any written information about radiotherapy by a member of staff (e.g. doctor, radiographer or nurse specialist) before your radiotherapy?	Yes			No
8.	Was the information/arrangements for your first appointment at the radiotherapy department easy to understand?	Yes, completely		Yes, to some extent	No
9.	Were you told about the local cancer information and support service at the hospital (sometimes called cancer information centre)?	Yes			No
10.	Overall was the amount of information given to you before you started your radiotherapy:	Excellent, helped with my treatment	Satisfactory, met my needs		Poor, didn't help much Very poor, didn't help at all

Q	Question text	All Positive percent	Partly Positive percent	Neutral percent	Negative percent
11 .pt 1	Did you go to the Radiotherapy department before you started treatment to be given information and an explanation about radiotherapy (pre-treatment or planning)? Please note that responses to this question have been used to measure both a) whether the patient was invited (11.pt1) and b) if the patient found the visit helpful (11.p2).	Yes, and I found it helpful Yes, but it was not helpful			I wasn't invited, but it would have been helpfull wasn't invited, but it would not have been helpful
11 .pt 2	Did you go to the Radiotherapy department before you started treatment to be given information and an explanation about radiotherapy (pre-treatment or planning)? Please note that responses to this question have been used to measure both a) whether the patient was invited (11.pt1) and b) if the patient found the visit helpful (11.p2).	Yes, and I found it helpful			Yes, but it was not helpful
13 .	If you did look at the cancer centre or hospital website did you find the information you found there helpful?	Yes, very helpful	Yes, fairly helpful		No, not at all helpful

Q	Question text	All Positive percent	Partly Positive percent	Neutral percent	Negative percent
16	Were you told how many radiotherapy treatments (sometimes called visits or fractions) you would probably need?	Yes, very clearly		Yes, to some extent	No
17	Were you told how long in total your course of radiotherapy treatment would last?	Yes, very clearly		Yes, to some extent	No
18	Was your plan of treatment explained clearly to you by a member of staff?	Yes, very clearly		Yes, to some extent	No
19	Were you given information to help you manage the side effects of your treatment?	Yes, very clearly		Yes, to some extent	No
20	Was the information given to you by your radiographer at the treatment visit the same as you were told by the doctor/radiographer at your clinic visit?	Yes, exactly the same		It was a little different	No, it was completely different
21	Was there someone in the hospital who you could talk to about any worries or fears you might have?	Yes, in the radiotherapy department Yes, elsewhere in the hospital (e.g. clinical nurse specialist or chaplain)			No, but I would have liked to talk to someone
23	If you travelled by car, was it easy to park?	Yes			No

Q	Question text	All Positive percent	Partly Positive percent	Neutral percent	Negative percent
24 .	How soon after your appointment time did your radiotherapy usually start?	On time or within 20 minutes of my appointment		Between 20 minutes and 1 hour of my appointment time	More than 1 hour after my appointment time
25 .	Were you informed of any delays?	Yes, always		Yes, sometimes	Never or rarely
26 . pt 1	What was the environment of the radiotherapy department like in respect of the waiting room?	Very good	Good		Poor Very poor
26 . pt 2	What was the environment of the radiotherapy department like in respect of the treatment room?	Very good	Good		Poor Very poor
26 . pt 3	What was the environment of the radiotherapy department like in respect of the department as a whole?	Very good	Good		Poor Very poor
27 .	Did you feel the changing facilities allowed you to maintain your dignity?	Yes		Yes, to some extent	No
28 .	Were you told that you could communicate with the radiographers outside the room during treatment?	Yes, both on TV and by speaking Yes, only on TV Yes, only by speaking			No
29 .	Did you feel that staff took adequate care whilst helping you get into the right position for your treatment?	Yes, definitely		Yes, to some extent	No

Q	Question text	All Positive percent	Partly Positive percent	Neutral percent	Negative percent
30	If you had any questions about the radiotherapy, did you have the opportunity to discuss these with the radiographer?	Yes, completely		Yes, to some extent	No
32	Did you have a regular formal review of your treatment (usually called the review clinic) by a member of the clinical team (e.g. doctor or radiographer)?	Yes			No
33	Did hospital staff give you information about support or self-help groups for people with cancer?	Yes			No, but I would have liked information
35	Have you been given a number to call if you have any problems in relation to your radiotherapy?	Yes			No
36	Do you know what the arrangements are for your next visit to see your consultant or other member of staff?	Yes			No
37	Were you given written information about what to expect in the few weeks following treatment and your post treatment care?	Yes			No

Q	Question text	All Positive percent	Partly Positive percent	Neutral percent	Negative percent
38 . pt 1	<p>Overall was the amount of information given to you at the start of your radiotherapy:</p> <p>Please note that responses to this question have been used to measure both a) whether the patient was given information (38.pt1) and b) the quality of information given (38.p2).</p>	Yes			No
38 . pt 2	<p>Overall was the amount of information given to you at the start of your radiotherapy:</p> <p>Please note that responses to this question have been used to measure both a) whether the patient was given information (38.pt1) and b) the quality of information given (38.p2).</p>	Excellent, helped with my treatment	Satisfactory , met my needs		Poor, didn't help much Very poor, didn't help at all
39 .	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 have liked to have been
40 .	Did you feel that staff took account of what mattered to you?	Yes, always		Yes, sometimes	No
41 .	Did you feel that the staff treated you with compassion and understanding during your treatment?	Yes, always		Yes, sometimes	No

Q	Question text	All Positive percent	Partly Positive percent	Neutral percent	Negative percent
42 .	Overall, how would you rate your care?	Excellent Very good	Good	Fair	Poor Very poor

14 APPENDIX C - THE QUESTIONNAIRE

(Overleaf)

Radiotherapy Patient Experience Survey

This questionnaire is about your radiotherapy treatment. Its purpose is to provide information which can help the NHS monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?

The questions should be answered by the person who has received radiotherapy treatment. If that person needs help to complete the questionnaire, the answers should be given from their point of view – not the point of view of the person who is helping.

Completing the questionnaire

For each question please tick clearly inside the box that is closest to your views using a **black or blue pen**. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire. Once completed, please return the questionnaire using the stamped addressed envelope provided. You do not need to use a stamp – the postage is already paid.



If you would prefer, you may also complete this survey online at:
[www.quality- health.co.uk/ sr14](http://www.quality-health.co.uk/sr14)

To do this you will need to enter the unique login details which can be found on the letter attached with this survey.

IMPORTANT INFORMATION

Taking part in this survey is voluntary

To make sure the information we collect is useful, we need to collect some personal details from you. This information is very general and you cannot be specifically or uniquely identified.

None of the staff who treated you will know if you respond, and all answers you provide will be entirely confidential. Published reports will not contain any personal details.

The results from this survey will be used to help us understand the views and experiences of patients and to measure and improve the quality of healthcare services in Scotland.

If you have any queries about the questionnaire, please call the FREEPHONE helpline number on 0800 783 1775.

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

CONSENT

The first few questions are about consent. A consent form is signed so that the hospital has your permission to give you treatment. These questions relate to your consent for radiotherapy.

1. When you gave your consent, to what extent did you understand what the **benefits** of radiotherapy were?
 - 1 I understood completely
 - 2 I understood to some extent
 - 3 I did not understand at all
 - 4 Don't know / can't remember
2. When you gave your consent, to what extent did you understand what the **side-effects** of radiotherapy were?
 - 1 I understood completely
 - 2 I understood to some extent
 - 3 I did not understand at all
 - 4 Don't know / can't remember
3. Were you given the opportunity to ask questions before giving consent?
 - 1 Yes → **Go to Q4**
 - 2 No → **Go to Q5**
 - 3 Don't know / can't remember
→ **Go to Q5**
4. If you did ask questions, were you satisfied with the answers that you received?
 - 1 Yes, completely
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember
5. Did you have confidence in the doctor or other health professional who took your consent for your radiotherapy?
 - 1 Yes, completely
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember

6. Were you treated with dignity and respect by the doctor or other health professional who took your consent for your radiotherapy?
 - 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember

INFORMATION BEFORE RADIOTHERAPY TREATMENT

These questions focus on the information you received about radiotherapy before your first appointment for planning (sometimes called simulator) for your radiotherapy.

7. Were you given or sent any written information about **radiotherapy** by a member of staff (e.g. doctor, radiographer or nurse specialist) before your radiotherapy?
 - 1 Yes
 - 2 No
 - 3 Don't know / can't remember
8. Was the information/arrangements for your **first** appointment at the radiotherapy department easy to understand?
 - 1 Yes, completely
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember
9. Were you told about the local cancer information and support service at the hospital (sometimes called cancer information centre)?
 - 1 Yes
 - 2 No
 - 3 Don't know / can't remember

- 10.** Overall was the amount of information given to you **before you started** your radiotherapy:
- 1 Excellent, helped with my treatment
 - 2 Satisfactory, met my needs
 - 3 Poor, didn't help much
 - 4 Very poor, didn't help at all
 - 5 I was not given any information before my radiotherapy started

- 11.** Did you go to the Radiotherapy department before you started treatment to be given information and an explanation about radiotherapy (pre-treatment or planning)?
- 1 Yes and I found it helpful
 - 2 Yes, but it was not helpful
 - 3 I wasn't invited, but it would have been helpful
 - 4 I wasn't invited, but it would not have been helpful
 - 5 No, as I was unable to go
 - 6 Don't know / can't remember

WEBSITE INFORMATION

- 12.** Did you look for information about radiotherapy on the cancer centre or hospital website where you had your radiotherapy?
- 1 Yes → **Go to Q13**
 - 2 No → **Go to Q14**

- 13.** If you **did** look at the cancer centre or hospital website did you find the information you found there helpful?
- 1 Yes, very helpful
 - 2 Yes, fairly helpful
 - 3 No, not at all helpful
 - 4 I did not find any information about radiotherapy on the website
 - 5 Don't know / can't remember
- } → **Go to Q15**

- 14.** If you **did not** look at the cancer centre or hospital website, was this because:
- 1 Didn't need to
 - 2 Didn't want to
 - 3 Didn't know there was any information on the website
 - 4 No internet access
 - 5 Some other reason

ABOUT YOUR RADIOTHERAPY

- 15.** Did you have **the majority** of your radiotherapy as an inpatient or as an outpatient?
- 1 I had the majority of my radiotherapy as an **inpatient**
 - 2 I had the majority of my radiotherapy as an **outpatient**
 - 3 Don't know / can't remember
- 16.** Were you told how many radiotherapy treatments (sometimes called visits or fractions) you would probably need?
- 1 Yes, very clearly
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember
- 17.** Were you told how long in total your course of radiotherapy treatment would last?
- 1 Yes, very clearly
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember
- 18.** Was your plan of treatment explained clearly to you by a member of staff?
- 1 Yes, very clearly
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember

19. Were you given information to help you manage the side effects of your treatment?

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

20. Was the information given to you by your **radiographer** at the treatment visit the same as you were told by the **doctor/radiographer** at your clinic visit?

- 1 Yes, exactly the same
 2 It was a little different
 3 No, it was completely different
 4 Don't know / can't remember

21. Was there someone in the hospital who you could talk to about any worries or fears you might have?

- 1 Yes, in the radiotherapy department
 2 Yes, elsewhere in the hospital (e.g. clinical nurse specialist or chaplain)
 3 No, but I would have liked to talk to someone
 4 No, but I didn't need to talk to anyone
 5 Don't know / can't remember

DAILY TREATMENT VISITS

22. How did you **usually** get to the hospital where you had your radiotherapy?

- 1 By car → **Go to Q23**
 2 By public transport (bus, train, taxi) → **Go to Q24**
 3 By ambulance / hospital transport → **Go to Q24**
 4 I walked / cycled → **Go to Q24**

23. If you travelled by car, was it easy to park?

- 1 Yes
 2 No
 3 I was dropped off so didn't need to park

24. How soon after your appointment time did your radiotherapy **usually** start?

- 1 On time or within 20 minutes of my appointment
 2 Between 20 minutes and 1 hour of my appointment time
 3 More than 1 hour after my appointment time
 4 It varied from visit to visit
 5 Don't know / can't remember

25. Were you informed of any delays?

- 1 Yes, always
 2 Yes, sometimes
 3 Never or rarely
 4 There were no delays
 5 Don't know / can't remember

26. What was the environment of the radiotherapy department like in respect of?

a. The waiting room

- 1 Very good
 2 Good
 3 Poor
 4 Very poor

b. The treatment room

- 1 Very good
 2 Good
 3 Poor
 4 Very poor

c. The department as a whole

- 1 Very good
 2 Good
 3 Poor
 4 Very poor

27. Did you feel the changing facilities allowed you to maintain your dignity?

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

28. Were you told that you could communicate with the radiographers outside the room during treatment?

- 1 Yes, both on TV and by speaking
 2 Yes, only on TV
 3 Yes, only by speaking
 4 No
 5 Don't know / can't remember

29. Did you feel that staff took adequate care whilst helping you get into the right position for your treatment?

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

30. If you had any questions about the radiotherapy, did you have the opportunity to discuss these with the radiographer?

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

31. During your **last course** of radiotherapy, how many treatments (sometimes called visits or fractions) did you have?

- 1 1-5
 2 5-10
 3 More than 10
 4 Don't know / can't remember

32. Did you have a regular formal review of your treatment (usually called the review clinic) by a member of the clinical team (e.g. doctor or radiographer)?

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

INFORMATION ABOUT SUPPORT

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

- 1 Yes → **Go to Q34**
 2 No, but I would have liked Information → **Go to Q35**
 3 No, but I would not have wanted this information → **Go to Q35**
 4 It was not necessary I already had this information → **Go to Q35**
 5 Don't know / can't remember → **Go to Q35**

34. If yes, what type of groups were you given information about? (**Please tick all that apply**)

- 1 General cancer support groups in my area
 2 Support groups for my specific type of cancer in my area
 3 National cancer charities
 4 Other groups

FOLLOWING TREATMENT

The next few questions are about information now that your radiotherapy has been completed.

35. Have you been given a number to call if you have any problems in relation to your radiotherapy?

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

36. Do you know what the arrangements are for your next visit to see your consultant or other member of staff?

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

37. Were you given written information about what to expect in the few weeks following treatment and your post treatment care?

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

YOUR OVERALL RADIOTHERAPY CARE

38. Overall was the amount of information given to you **at the start** of your radiotherapy:

- 1 Excellent, helped with my treatment
 2 Satisfactory, met my needs
 3 Poor, didn't help much
 4 Very poor, didn't help at all
 5 I was not given any information at the start of my radiotherapy
 6 Don't know / can't remember

39. 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
 4 No, I did not wish to be involved
 5 Don't know / can't remember

40. Did you feel that staff took account of what mattered to you?

- 1 Yes, always
 2 Yes, sometimes
 3 No
 4 Don't know / can't remember

41. Did you feel that the staff treated you with compassion and understanding during your treatment?

- 1 Yes, always
 2 Yes, sometimes
 3 No
 4 Don't know / can't remember

42. Overall, how would you rate your care?

- 1 Excellent
 2 Very good
 3 Good
 4 Fair
 5 Poor
 6 Very Poor

ABOUT YOU

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

43. What year were you born?

(Please write in) e.g.

1	9	4	4
---	---	---	---

--	--	--	--

Y Y Y Y

44. Are you male or female?

- 1 Male
 2 Female

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

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

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

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

47. To which of these ethnic groups would you say you belong? **(Tick one box only)**

a. WHITE

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

b. MIXED

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

c. ASIAN OR ASIAN BRITISH

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

d. BLACK OR BLACK BRITISH

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

e. OTHER ETHNIC GROUP

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

OTHER COMMENTS

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

Was there anything particularly good about your care?

Was there anything that could have been improved?

Any other comments?

Thank you for your help.

Please return this questionnaire in the envelope provided.
You do not need to use a stamp – the postage is already paid.



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