



# Scottish Cancer Patient Experience Survey 2018: Free-text Analysis

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# 1. Executive Summary

## 1.1 Introduction

The Scottish Cancer Patient Experience Survey is a national postal survey jointly funded by the Scottish Government and Macmillan Cancer Support, and run in partnership with Public Health Scotland (PHS). The survey asks patients about their experience of cancer care and the support they received, from diagnosis through their treatment and aftercare.

Over 5,000 patients who received cancer care in Scotland responded to the 2018 [Scottish Cancer Patient Experience Survey \(SCPES\) 2018](#)<sup>1</sup>. This report presents the results and analysis of the free-text comments provided in the questionnaire. The survey included six free-text comment boxes relating to different aspects of a patient's cancer journey, from the lead up to diagnosis to their overall experience of their care. Of the 5,001 patients who took part, 3,315 (66 per cent) left at least one free-text comment. In total, 9,320 comments were made by participants.

## 1.2 Methods

Free-text responses were evaluated using thematic analysis to identify common themes amongst responses. Analysis identified key positive and negative issues highlighted by patients in relation to their experience of cancer care. Neutral, factual and miscellaneous comments were also identified. Responses were then categorised into key themes and sub-themes by assigning comments to codes based on similar topics arising from responses. These codes were then compared across all the data to ensure consistency.

## 1.3 Findings

Examining responses to the six comment boxes in the survey showed that overall there were more positive than negative free-text responses. Positive and negative comments were analysed separately and responses grouped into common themes and sub-themes. Despite there being a larger number of positive comments, the length, breadth and detail of negative comments has led to greater discussion of negative themes across responses.

### Positive comments

Analysis of the positive comments resulted in the development of several discrete themes; feeling confident in the system, feeling that individual needs were met, efficient processes and positive comments on structures.

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<sup>1</sup> <https://www.gov.scot/publications/scottish-cancer-patient-experience-survey-2018-national-report/>

The most common theme identified within the positive comments was feeling that individual needs were met. Many comments related to examples of good support, positive third sector support, being provided with clear and detailed information and patients being involved in decisions about their treatment.

Many respondents expressed an overall positive care experience, with the most commonly referenced sub-themes relating to receiving good clinical care, good support, efficient processes and clear information

### **Negative comments**

Negative comments relating to patients' experiences of cancer care were similarly categorised into four main themes; not feeling confident in the system, not feeling that individual needs were met, and negative experiences of processes and structures.

More than a third of negative comments related to people not feeling confident in the system. They described particular concern about the difficulties they experienced getting diagnosed and referred for treatment, receiving inadequate aftercare, and having inadequate contact with the appropriate medical professional.

Not feeling that individual needs were met was also an important concern for respondents. Factors which contributed to this feeling included a lack of information about their treatment, poor communication and a lack of emotional support.

### **Neutral Comments**

Neutral comments written by participants describing their cancer care experiences were coded into three themes; okay care, patient led peer support and support from family and friends.

Almost three quarters of all neutral comments referred to support provided by family and friends during diagnosis and throughout treatment and aftercare.

## 2. Introduction

Results from the quantitative analysis of the 2018 [Scottish Cancer Patient Experience Survey \(SCPES\)](#)<sup>2</sup>, indicated that patients were generally very positive about their experience of cancer care services. The vast majority of people (95 per cent) rated their overall experience of cancer care positively, and 97 per cent of respondents reported that they were always treated with dignity and respect by health care professionals treating them.

Greater understanding of patients' experiences can be gained by analysing responses to the survey's free-text comment boxes. The free-text comments provide deeper insight into aspects of care which can strongly affect the experiences of patients undergoing cancer treatment. Analysis of qualitative responses can also provide invaluable details about particular features of a patient's cancer care and shed light on areas affecting people with specific circumstances. A comment box was included at the end of each section of the questionnaire, allowing participants the opportunity to comment on each individual stage of their cancer diagnosis and care.

This is the second time a qualitative analysis of a Cancer Patient Experience Survey has been conducted in Scotland<sup>3</sup>. This report follows a similar thematic analysis and has been based on the main themes explored in the 2015 Scottish Cancer Patient Experience Survey, although the number and wording of individual free-text questions differed between the two reports.

## 3. Methods

### About the Survey

The Scottish Cancer Patient Experience Survey contained six free-text comment boxes. Free-text comment boxes were placed at the end of each section of the survey to allow participants to discuss further information about the issue covered in the preceding section.

Questionnaires could be completed on paper or on-line. Free-text comments were transcribed and any details which could lead to an individual being identified were redacted. Prior to analysis, socio-demographic and clinical data were anonymised and given an identifier which could be linked to comments. Table 1 shows the question asked in each comment box and details the main topics of the preceding section in the questionnaire.

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<sup>2</sup> <https://www.gov.scot/publications/scottish-cancer-patient-experience-survey-2018-national-report/>

<sup>3</sup> <https://www.gov.scot/publications/scottish-cancer-patient-experience-survey-2015-16-analysis-free-text/>

**Table 1: Comment Boxes**

	Question Topic: If there is anything else you would like to tell us about...	Preceding Questionnaire Section Headings
Comment Box 1 (Survey question 11)	The lead-up to your cancer diagnosis, or the way you found out you had cancer	Getting diagnosed, Finding out about your cancer
Comment Box 2 (Survey question 18)	The way decisions were made about your treatment	Deciding the best treatment for you
Comment Box 3 (Survey question 28)	Your operation / radiotherapy / chemotherapy treatment	Operations, Radiotherapy and Chemotherapy
Comment Box 4 (Survey question 34)	The care you received when you were in hospital for cancer care	Hospital care
Comment Box 5 (Survey question 49)	Any other support you received during your cancer care, including from your GP Practice and third sector organisations	Support from Health and Social Services, Other Support,
Comment Box 6 (Survey question 61)	Your experience of cancer care	Your overall experience

A total of 8,090 surveys were sent to eligible respondents, of which 5,001 cancer patients responded to the survey, giving an overall response rate of 62 per cent. Of those, 3,315 participants (66 per cent) left at least one free-text comment. Overall, 9,320 comments were left by those 3,315 participants across the six comment boxes. The comment box which generated the most comments was Comment Box 1 - lead up to diagnosis (2,160 comments). Comment Box 2 – way decisions were made about your treatment (1,198 comments), received the fewest number of comments.

## About the Survey Participants

The survey sample was drawn from individuals aged 16 or over who had inpatient hospital records with a mention of cancer between 1 January and 30 September 2017, and a confirmed cancer diagnosis date between 1 July 2016 and 31 March 2017 on the Scottish Cancer Registry. A total of 8,090 surveys were sent out and 5,001 completed surveys were returned.

The socio-demographic and clinical characteristics of all participants and those who left at least one comment are described in **Appendix 1**. Comparisons indicate no large differences between the two groups. Fifty-six per cent of respondents who submitted at least one free-text comment were female and forty-four per cent were male.

## Data Analysis

The free-text comments were analysed using thematic analysis, and NVivo software was used as a data management tool. Positive and negative comments were identified, and is presented separately in the results section, due to the volume and nature of the data. Comments were coded into relevant categories depending on the content of the response. Each comment could be coded into multiple categories if a participant touched on more than one sub-theme in a single free-text box.

The results of the free-text analysis are presented using a range of approaches. First, a breakdown of each of the six comment boxes is given. This is followed by an overview of the number of positive, negative and neutral comments and sub-themes, alongside a detailed description of the main themes arising from the thematic analysis. Within each section a more comprehensive breakdown of each of the positive, negative and neutral sub-themes is provided together with illustrative examples of experiences shared by survey participants. Any disclosive information has been removed from individual's comments, but they are otherwise presented verbatim.

## 4. Results

Overall, there were more positive (4,176) than negative (2,285) comments. In addition to this, 1,105 participants made both positive and negative remarks within the same comments box. Top level categories were used to sort responses into positive, negative and positive/negative comments. This last category reflected the fact that many participants had variable experiences, indicating both positive and negative aspects of their experiences within a single comment. Respondents also entered 1,690 factual or neutral comments, and 64 miscellaneous comments.

Factual comments were defined as comments where respondents stated details of their cancer diagnosis or treatment (such as their cancer type, symptoms or clinical tests they received) but did not provide any information relating to their care experiences or personal opinions of their care, treatment or support. Comments were coded as 'Neutral' when a patient responded that their care was 'okay', they did not have any further comment to add or that the free-text box was not applicable to them. Comments were also recorded as 'Neutral' if they discussed patient-led peer support or support they received from family and friends.

For each of the six free-text comment boxes, there were more positive than negative comments (Appendix 2). However, a similar proportion of positive and negative comments appeared in Comment Box 1 (lead up to diagnosis), suggesting that patients' experiences of diagnosis were more equally divided. Comment Box 4 (care received in hospital for cancer) had the highest proportion of positive to negative comments, suggesting that participants were proportionally happier with the care they received when they were in hospital.

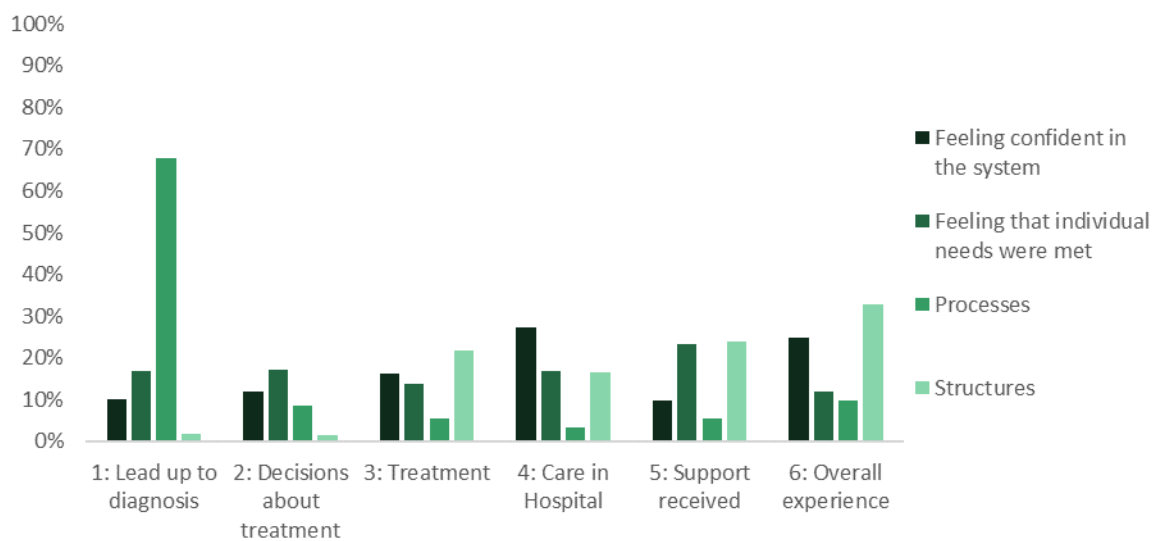


## 4.1 Analysis of Individual Comment Boxes

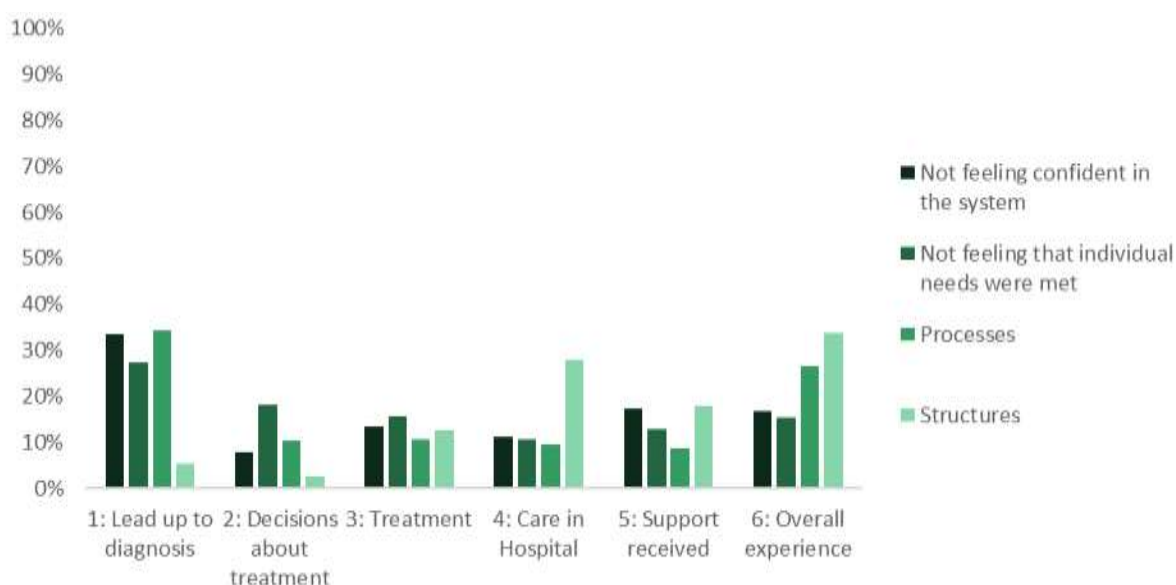
Each of the six free-text comment boxes relates to a different stage in a cancer patient’s journey, and quantitative analysis highlighted the relevance of specific themes at each stages. For each free-text question, patients’ responses were group into four main positive and negative themes: feeling confident in the system/not feeling confident in the system, feeling that individual needs were met/not feeling that individual needs were met, processes and structures. Within each of these themes, responses were grouped in the sub-themes. The content of each theme and sub-theme, alongside illustrative examples of participants’ responses, will be explored in more detail in sections 4.2 and 4.3.

**Figure 1** and **Figure 2** illustrate the distribution of each of the four main positive and negative themes across the six free-text comment boxes. It can be seen that efficient processes were a high priority for patients’ in the lead up to their diagnosis. Sixty-eight per cent of all positive references to processes and quick treatment were left in comment box 1. Similarly, respondents were more likely to refer to structures, such as transport assistance and the availability of local care facilities when discussing their treatment, support available and overall care experience. Patients were most concerned about ineffective processes and not feeling confident in the system when discussing the lead up to their diagnosis.

**Figure 1: Distribution of Positive Themes across Comment Boxes**



**Figure 2: Distribution of Negative Themes across Comment Boxes**



In order to explore the key aspects of a patient’s experience at each stage of their cancer journey, analysis has been used to determine the most prevalent sub-themes discussed in each of the six free-text comment boxes. Bar charts have been used to illustrate all sub-themes which represented a minimum of 8 per cent of the references received for the corresponding comment box. Any sub-themes which represented less than 8 per cent of the total references for that comment box have been combined into the ‘Other’ section for each chart. Respondents’ comments have not been double counted within any sub-theme, however, any individual respondent may have made reference to more than one sub-theme within a single comment box.

## **Comment Box 1: The lead up to your cancer diagnosis, or the way you found out you had cancer**

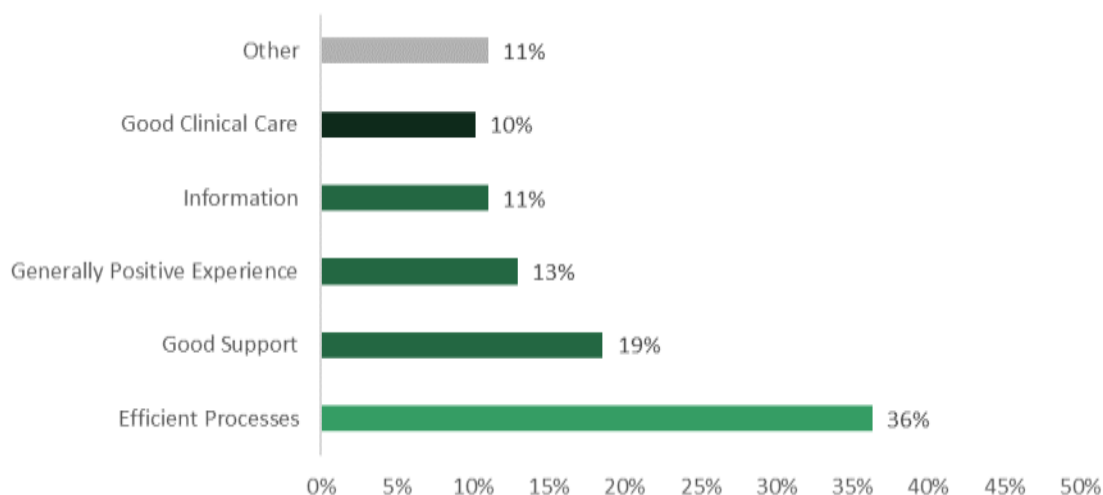
In the first free-text comment box, patients were asked:

*“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.”*

### **Positive**

Analysis of the positive sub-themes for the first comment box (**Figure 3**) identified the key themes respondents valued: efficient processes; good support; having a generally positive experience; clear information; and good clinical care. 36% of positive comments for this question were related to efficient processes.

**Figure 3: The lead-up to cancer diagnosis: Positive sub-themes**



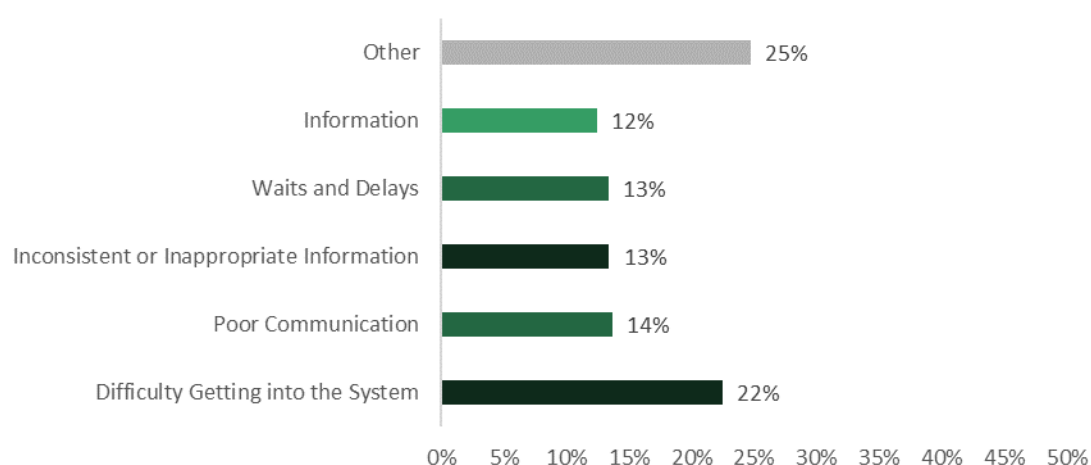
Notably, the vast majority of references to efficient processes across the whole survey appeared in comment box 1 (71%), and related to experiences of diagnosis and the lead up to diagnosis.

Of those references combined in the 'Other' category, the majority discussed patients' positive experiences of receiving quick treatment and being involved in the decisions about their cancer treatment.

## Negative

Analysis of the negative sub-themes (**Figure 4**) highlighted a range of factors. Almost a quarter of these comments described difficulty getting into the system at the outset of patients' cancer care journeys. Other issues reported here were related to: communication, information; and waits and delays.

**Figure 4: The lead-up to cancer diagnosis: Negative sub-themes**



References that did not fall into the top five categories for this comment box made up 25 per cent of all references. They touched on each of the four main themes,

although many concentrated on negative experiences of processes. This included experiences of inefficient administration and seventy-six per cent of all the survey comments referring to insufficient screening tests. Several participants also commented on a lack of emotional support in the lead-up to cancer diagnosis. Twenty-eight per cent of all references to lack of emotional support or responsiveness were left in response to this free-text question.

## Comment Box 2: The way decisions were made about your treatment

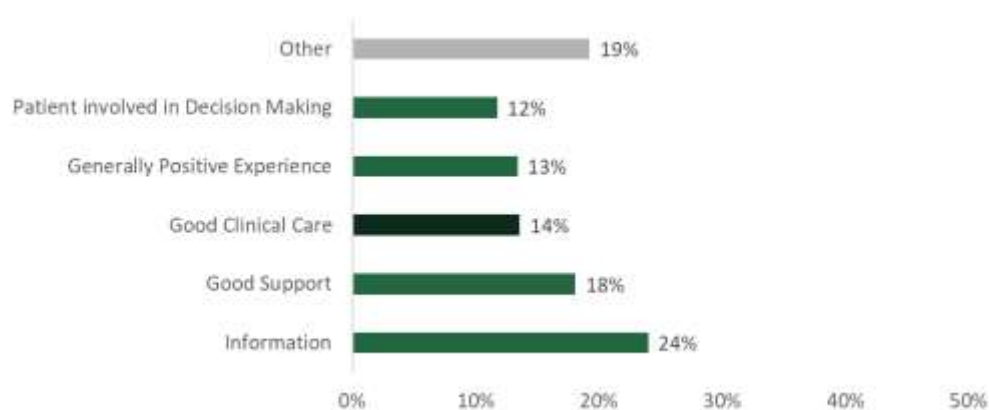
Comment Box 2 asked patients:

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

### Positive

Analysis of the positive sub themes for comment box 2 (**Figure 5**) indicated that respondents valued the availability of information and support, in relation to making decisions about treatment. Patients appreciated having their treatment plan explained clearly and having a full understanding of their upcoming procedures. Results from the quantitative study found that eight-seven per cent of people felt that their treatment options were explained fully to them prior to treatment and around four out of five patients responded positively about being involved in decisions concerning their cancer care. Other key sub-themes reported included: good clinical care; generally positive experience; and being involved in decision making.

**Figure 5: The way decisions were made about treatment: Positive sub-themes**

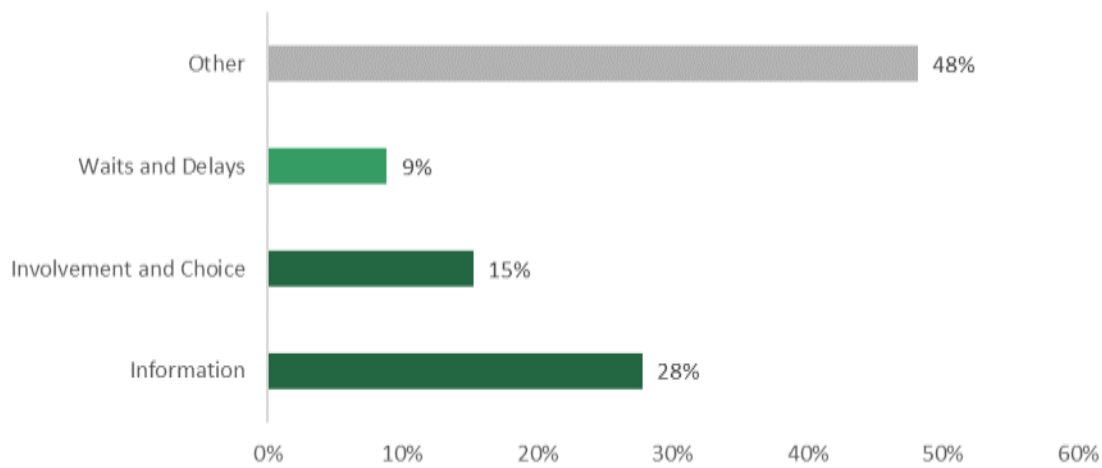


Comments addressing ‘Other’ sub-themes were spread across many sub-themes and touched on several issues including efficient processes, positive experiences of third sector support and quick treatment. Over sixty per cent of all comments about having “trust in the system” were recorded in patients’ responses to this question.

## Negative

Analysis of the negative sub-themes (**Figure 6**) suggested the three key factors related to making decisions about treatment were a lack of information, insufficient involvement and choice in decisions regarding treatment, and waits and delays. It was clear from qualitative responses that patients found a lack of available information and detailed explanation of their cancer treatment detrimental to their experience as well as adding to their overall feelings of anxiety. Some also commented on not feeling that they had sufficient information to be prepared for, or more involved in, decisions regarding their treatment.

**Figure 6: The way decisions were made about treatment: Negative sub-themes**



Almost half of all negative references in this free-text comment box have been grouped as “Other”, due to small numbers of references being spread across a broad range of sub-themes. These comments focused particularly on patients’ experiences being negatively affected by poor communication and receiving inconsistent or incorrect information. There were also several references to a lack of emotional support.

## Comment Box 3: Your operation/radiotherapy/chemotherapy treatment

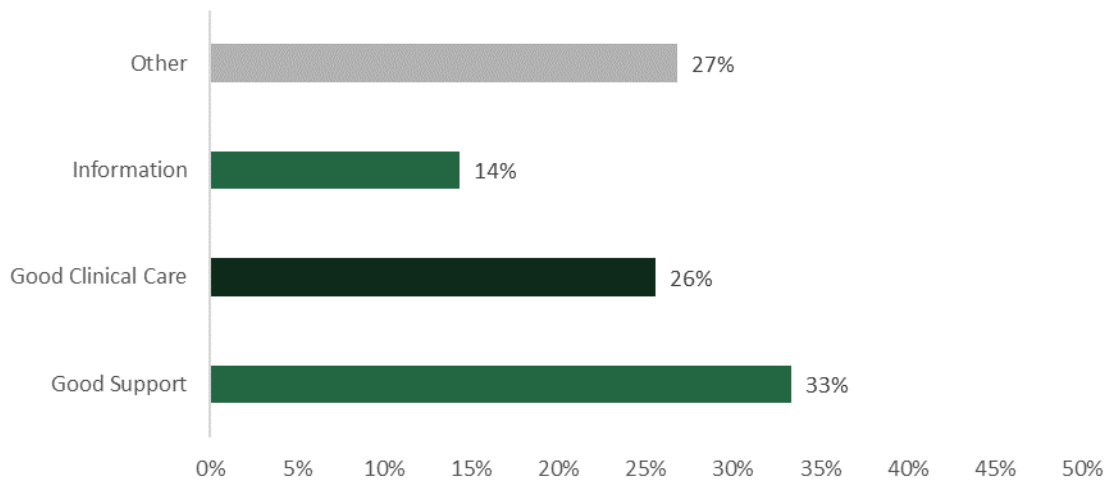
Comment Box 3 asked patients to discuss:

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

## Positive

Analysis of the positive sub-themes for comment box 3 (**Figure 7**) highlighted three key factors in relation to patients’ positive experiences of undergoing operations and treatments. They focused on the two main areas of ‘Feeling that individual needs were met’ and ‘Feeling confident in the system’. A third of references related to the availability of good support, whilst patients also valued good clinical care and clear and detailed information.

**Figure 7: Your operation / radiotherapy / chemotherapy treatment: Positive sub-themes**

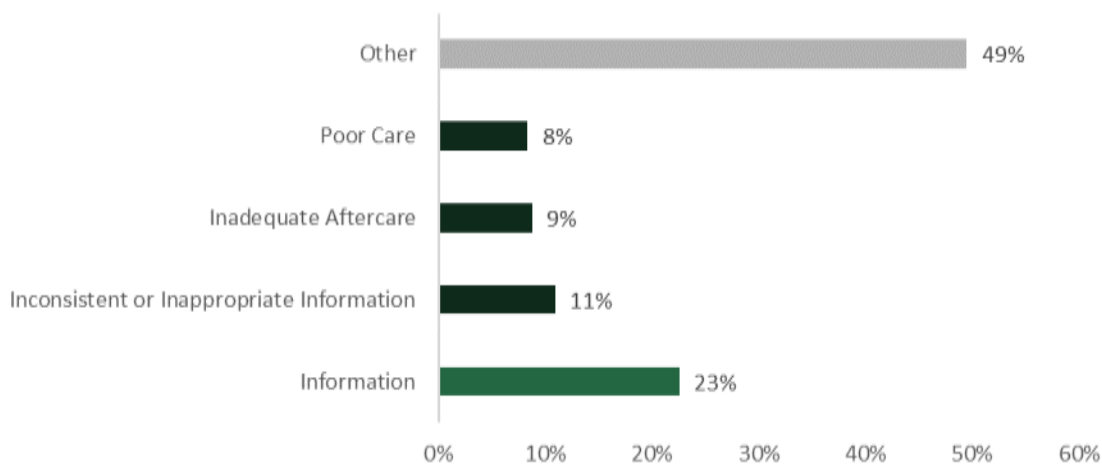


Two of the notable sub-themes captured in the comments coded as ‘Other’ were good aftercare and patients’ noting they had a “generally positive experience”.

### Negative

Analysis of the negative sub-themes (**Figure 8**) highlighted a range of factors related to patients’ experiences of undergoing operations or treatment. All four of the most popular sub-themes came from the themes ‘Not feeling individual needs were met’ and ‘Not feeling confident in the system’. A third of these comments were concerned with the provision of information, whilst other comments described issues related to care or aftercare. Once again, patients felt their experience during treatment was negatively impacted by not having sufficient information available to them; both prior to treatment and pertaining to aftercare and potential side effects of treatment.

**Figure 8: Your operation / radiotherapy / chemotherapy treatment: Negative sub-themes**



The high percentage of total references grouped into “Other” reflects the wide range of comments spread across remaining sub-themes. Participants touched on poor communication and a lack of emotional support during their care as well as waits and

delays for treatment. A small number of patients commented on their treatment taking place in an uncomfortable environment and a lack of local support or care facilities.

## Comment Box 4: The care you received when you were in hospital for cancer care

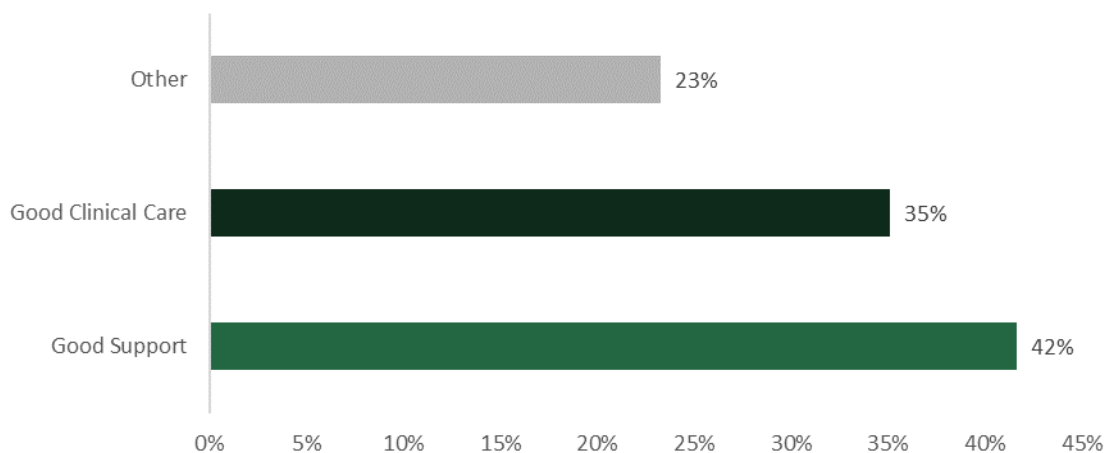
In Comment Box 4 participants were asked:

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

### Positive

Analysis of the positive sub-themes (**Figure 9**) indicated that good support and good clinical care were particularly highly valued in relation to participants’ experiences of being in hospital for cancer care, accounting for over three quarters of all comments left in comment box 4.

**Figure 9: The care you received when you were in hospital for cancer care: Positive sub-themes**

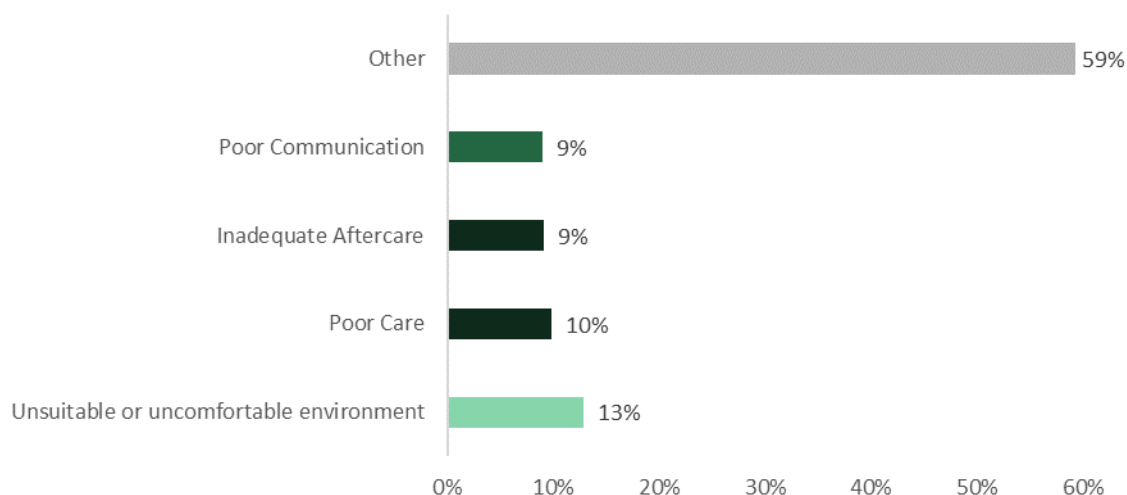


In addition to these two areas, patients also described their experiences of good post-operative care and the availability of clear information during their hospital stay. Almost half (47 per cent) of all positive comments about receiving treatment in a comfortable care environment were left in response to this question.

### Negative

The negative comments left in the free-text box (**Figure 10**) were spread more broadly across a range of sub-themes. Negative comments with the main theme of structures became more evident, with thirteen per cent of references discussing patients’ experiencing an unsuitable or uncomfortable environment while in hospital. Participants also commented on poor care, inadequate aftercare and poor communication.

**Figure 10: The care you received when you were in hospital for cancer care: Negative sub-themes**



The wide range of material discussed by patients when asked about their care in hospital is particularly evident by the broad spectrum of sub-themes encompassed in the 'Other' category. Comments were spread across all four of the main negative themes. Patients discussed experiencing fragmented care, evidence of problems with staffing levels and waits and delays for treatment. Fifty-four per cent of all negative comments relating to privacy were noted here with regard to their inpatient experience during cancer care.

### **Comment Box 5: Any other support you received during your cancer care, including from your GP Practice and third sector organisations**

In Comment Box 5, participants were asked:

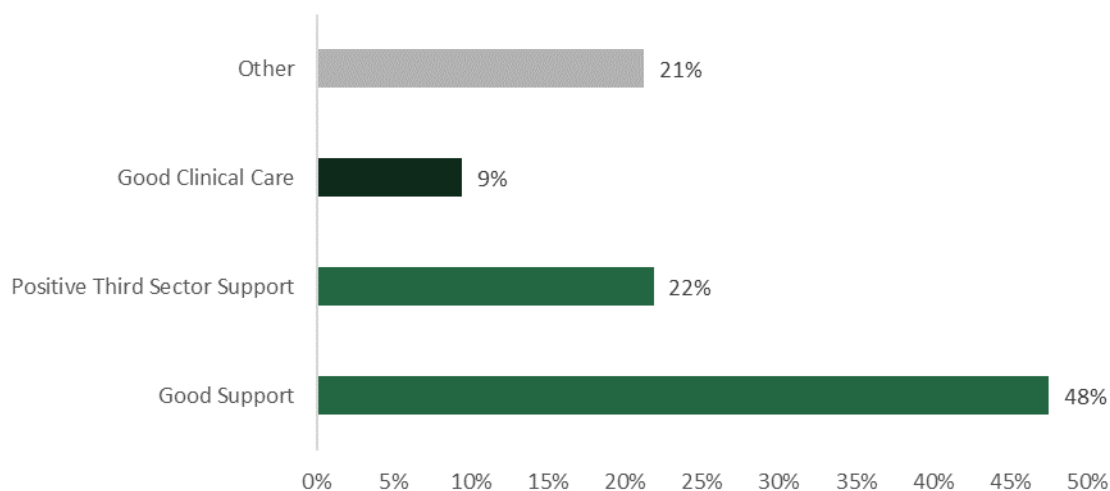
“If there is anything else you would like to tell us about any of the support you received during your cancer care, including from your GP Practice and third sector organisations, please do so here.”

#### **Positive**

Analysis of the positive sub-themes for comment box 5 (**Figure 11**) indicated that good support, both from consultants and GPs as well as third-sector organisations was greatly appreciated by many participants. Responses touched on staff being approachable and providing emotional support, as well as patients feeling supported by staff during treatment.



**Figure 11: Support you received during your cancer care, including from your GP Practice and third sector organisations: Positive sub-themes**

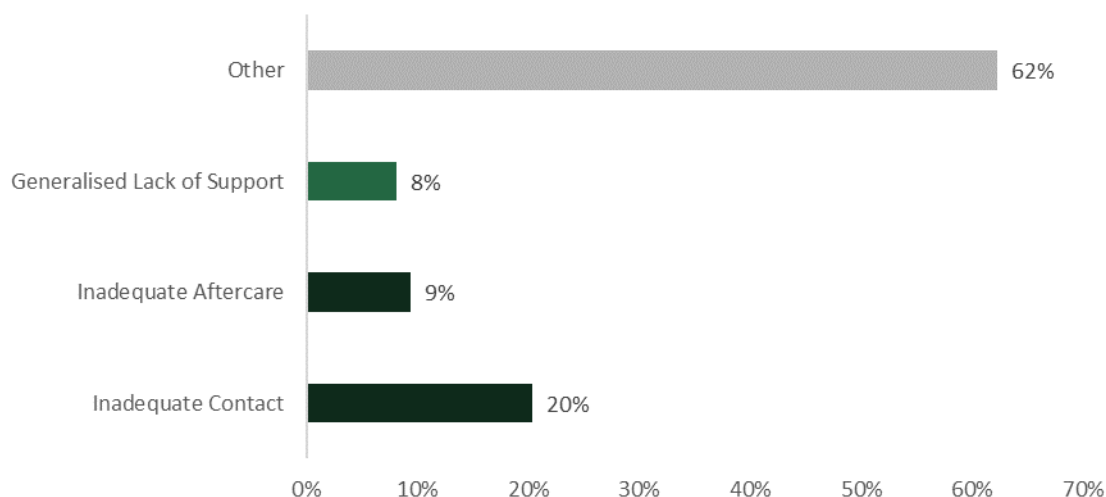


In addition to good overall support and clinical care, the provision of aftercare and good clear information and details of treatment were essential for patients to feel supported and confident in their cancer care. While providing details of any support they received, many participants noted the transport support they received from third sector organisations to travel to and from care centres. Forty two per cent of all positive references to transport assistance were left in response to this free-text box.

## Negative

Analysis of the negative sub-themes for comment box 5 (Figure 12) highlighted a range of factors in relation to patients' experiences of support, including: inadequate contact; inadequate aftercare; and general lack of support. Comments referenced feeling a lack of support both through a lack of time available to discuss treatment with medical staff, and a lack of provision for emotional support during and after treatment.

**Figure 12: Support you received during your cancer care, including from your GP Practice and third sector organisations: Negative sub-themes**



When discussing the level of support received during their cancer care, responses were spread across a wide range of themes, as illustrated by the large percentage of references that were group in 'Other'. Such comments made particular reference to not feeling that their individual needs were met, through a lack of information, third sector support and general emotional support throughout their cancer journey. This was reflected in the quantitative results from the 2018 survey, where only fifty-four per cent of those who wanted or needed help from the third sector were given sufficient information and forty per cent of people reported not receiving any information or support from the third sector. Comments also touched on negative aspects of process: waits and delays and unreliable organisational processes.

## Comment Box 6: Your experience of cancer care

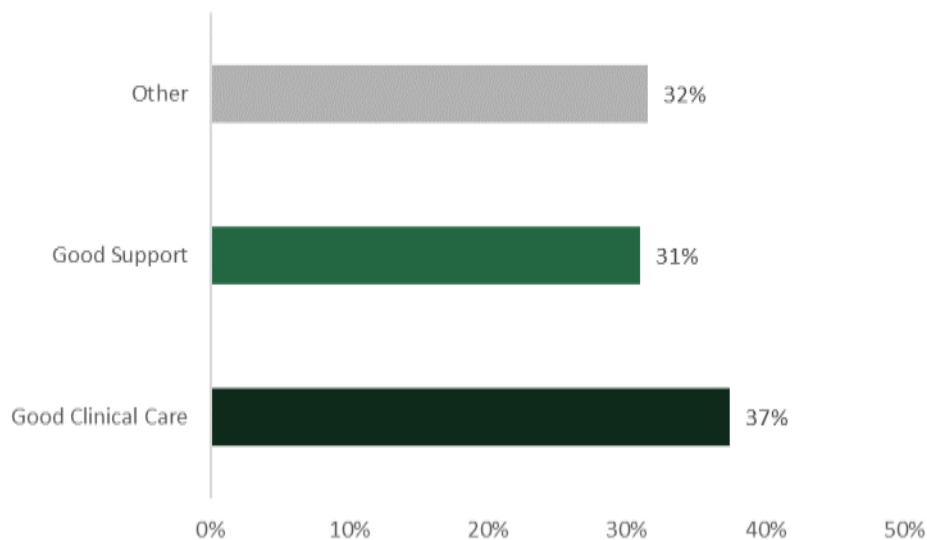
The final free-text question in the survey asked patients more broadly to share any additional comments on their experience of cancer care:

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

### Positive

Analysis of the positive sub-themes for comment box 6 (**Figure 13**) highlighted the importance of clinical care and support in relation to patients' overall experience of cancer care. Over two-thirds of all positive comments left fell into these two sub-themes.

**Figure 13: Your experience of cancer care: Positive sub-themes**

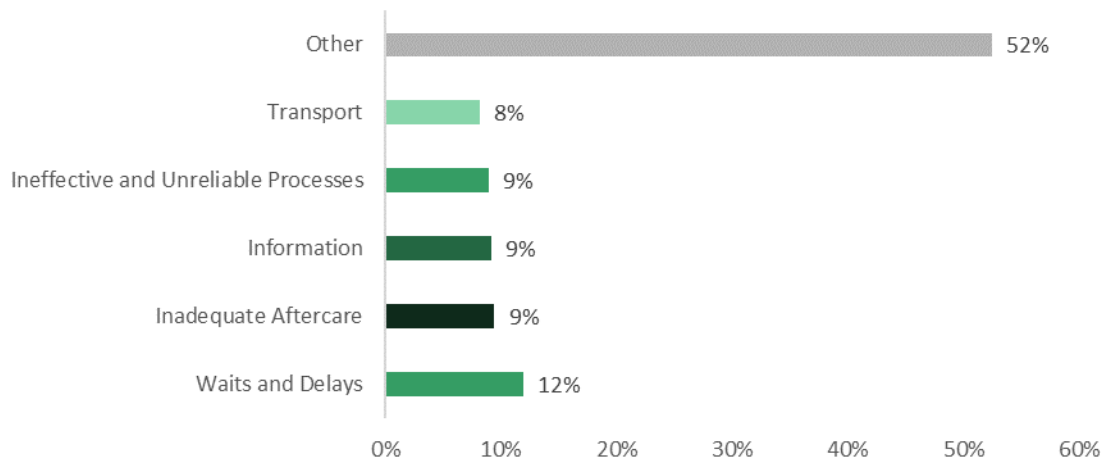


The remaining thirty-two per cent of responses were spread across all other sub-themes, but focused primarily on positive experience of efficient processes, receiving detailed information and good aftercare.

## Negative

Analysis of the negative sub-themes for comment box 6 (**Figure 14**) highlighted a broad range of factors in relation to patients' overall experiences of cancer care. Notable issues included: waits and delays; inadequate aftercare; information; ineffective and unreliable processes; and transport.

**Figure 14: Your experience of cancer care: Negative sub-themes**



As with the positive responses to this free-text question, the remaining comments written by patients covered a range of issues across all sub-themes. In particular respondents provided examples of their experiences of poor communication and fragmented care.

## 4.2 Positive Comments

Overall, participants in the survey made substantially more positive (4,176) than negative (2,285) comments about their cancer patient experience. However, positive responses were much shorter and less comprehensive than negative responses, as has been observed in other similar studies.<sup>4</sup> This means that, although there were substantially more positive comments, and the quantitative study indicated that vast majority of people (95 per cent) rated their overall experience of cancer care positively, the discussion of positive comments was often less in-depth and provided fewer details. Respondents' comments were often found to have referenced more than one sub-theme. No comments were double counted within any sub-theme, however, any individual respondent may have made reference to more than one sub-theme within a single comment box.

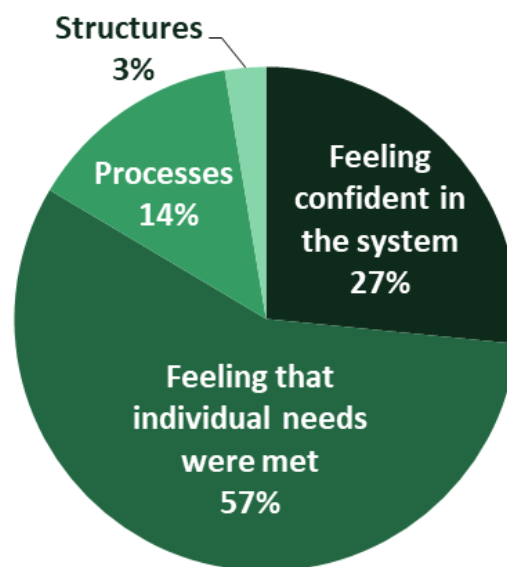
<sup>4</sup> See 'Scottish Cancer Patient Experience Survey 2015/16: Analysis of Free-text Comments'. Available at: <https://www.gov.scot/publications/scottish-cancer-patient-experience-survey-2015-16-analysis-free-text/>

The positive references were grouped into four main themes:

- Feeling confident in the system
- Feeling that individual needs were met
- Processes
- Structures

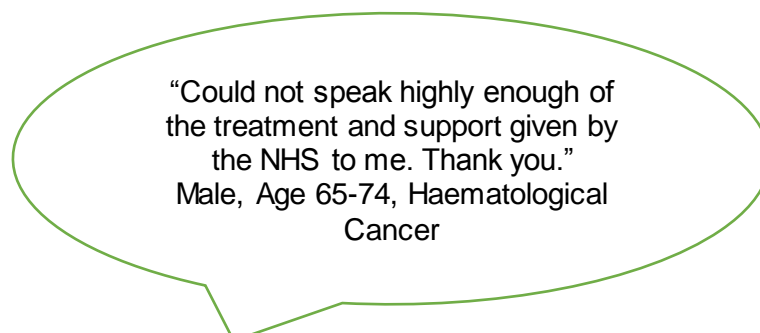
The distribution of responses across these four themes can be seen in **Figure 15**. The majority of positive references (57 per cent) included a discussion of patients' individual needs being met.

**Figure 15: Distribution of positive references across main themes**



Within each of these main themes, responses were grouped into sub-themes defining patients' experiences of cancer care. Positive comments were generally characterised by references to good support, good clinical care, efficient process and access to sufficient and relevant information. These sub-themes touch on all aspects of a patient's care from diagnosis, through treatment and inpatient care as well as aftercare and third sector support.

Some participants left generalised non-specific positive comments (214 references). These expressed an overall positive care experience or gratitude for the treatment they received. Participants also made specific reference to their appreciation of the NHS and NHS staff (151 references).



“Everything was highly commendable.”  
Female, Age 75+,  
Urological Cancer

“Nothing but thanks and gratitude”  
Female, Age 65-74, Breast Cancer

## Feeling that individual needs were met

Fifty seven per cent of all positive references related to patients expressing that they felt their individual needs were met. The vast majority of these comments described feeling that they had received good support from health professionals and third sector organisations. This group also described feeling that they had received the information they needed and were involved in decision making.

**Table 2: Feeling that individual needs were met references**

Sub-themes	Number of References
Good support	2,547
Positive and useful third-sector support	417
Information	862
Patient involved in decision making	206
Generally positive experience	567
<b>Total number of references</b>	<b>4,599</b>

### Good support

Across all six free-text comment boxes, there were 2,547 positive references to good support. Good support was described as being looked after by staff who were caring, supportive and approachable. Patients described staff as giving them confidence and treating them as an individual. Many comments noted the professionalism of staff and directly referenced the support provided by nurses and clinical nurse specialists (183 references). Respondents appreciated when staff provided emotional support by being cheerful, friendly and generally helpful. Patients specifically commented on the support they received from their GP (307 references). Many emphasised the role of the GP as being an important point of contact and support throughout the process, as well as being imperative in diagnosing their cancer or referring them for treatment.

“I found all of the staff at the hospital; were caring, considerate and full of compassion. I felt cared for and supported. Doctor, who carried out the first hospital diagnostic test and told me of the tumour, was particularly kind. I then spoke with the consultant to who was clear and concise in the information he gave, he allowed me time to process the information he was giving me and did not rush I feel that I had the best care possible form these doctors.”

Female, Age 45-54, Gynaecological Cancer

“My GP was amazing, They were so supportive and helpful to me throughout and beyond my treatment. I felt that at my GP practice I could open up and discuss how I really felt.”

Female, Age 45-54, Breast Cancer

“All staff amazing, kind, understanding, supportive.”

Male, Age 45-54, Sarcoma

## Positive third-sector support

Patients also commented (417 references) on the positive support they received from charities and third-sector organisations. (e.g. Macmillan, Maggie’s, Urological CANcers Aberdeen, CLAN Cancer Support Citizens Advice Scotland etc.). Respondents noted that these organisations provided an invaluable point of contact and information. In particular, 221 references were made about the positive support received from Macmillan. However, some participants noted that they had only found out about the support available from charities and other third-sector organisations later in their cancer treatment and were informed by family members or other patients. Many in this group would have found it more useful to have known about this support at the start of their cancer care.

“Prostate Cancer UK provided me with comprehensive literature regarding my condition, but also enabled me to speak to other men who had chosen different treatments with varying side effects. The best advice I was given was to take some time learning about the options available to me.”

Male, Age 75+, Prostate Cancer

“I had full consultation at every stage. Very impressed with Macmillan Cancer Charity – very helpful, kept informed and could contact at any time.”

Male, Age 65-74, Colorectal Cancer

“I have to say Macmillan have been very good with me and helped me with stuff that I needed to fill out and they did all that for me, which was great. The nursing staff were fantastic.”

Female, Age 65-74, Lung Cancer

“After my treatment I contacted the Ayrshire Cancer Centre who were very good with providing me with various therapies to aid my recovery and well-being.”

Male, Age 55-64, Breast Cancer

## Information

Respondents particularly valued being given thorough explanations of their cancer treatment options and clear detailed information, either in spoken or written form, to which they could refer after their appointment. Patients were positive about the sensitivity in which information was discussed, and also referred to the breadth of documentation and helpful leaflets provided after diagnosis. There was a total of 862 positive comments referencing clear information.

“The clinical staff were informative and sensitive towards me. They explained in full what the next procedure be and other options of treatment.”

Male, Age 55-64, Prostate Cancer

“I was treated with the utmost respect by the oncologist and they explained fully what treatment was best for me and gave me leaflets about the treatments for my reference.”

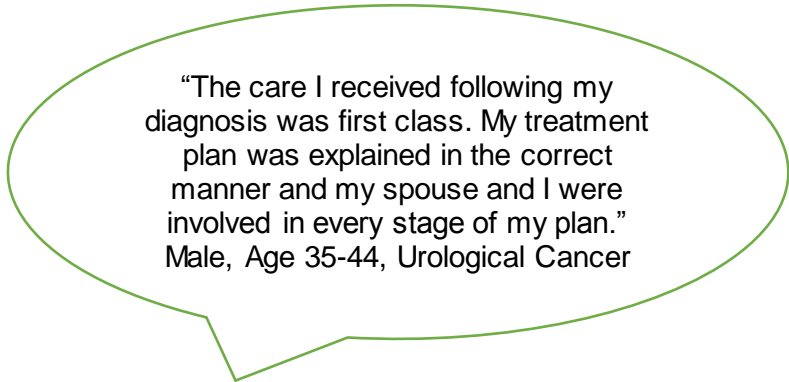
Female, Age 55-64, Upper Gastrointestinal Cancer

“Being told, in an informative and clear concise manner helped us understand.”

Male, Age 65-74, Haematological Cancer

## Patient involved in decision making

A number of respondents commented positively on being involved in decisions regarding their cancer treatment. Patients emphasised their appreciation for being given clear information and being involved in discussions relating to their treatment. Being informed of all options available, and supported in these discussions, were important issues. The opportunity to involve family members was also vital for many patients.



“The care I received following my diagnosis was first class. My treatment plan was explained in the correct manner and my spouse and I were involved in every stage of my plan.”  
Male, Age 35-44, Urological Cancer

## Feeling confident in the system

Twenty seven per cent of all positive references related to patients feeling confident in the system. The vast majority of these comments described feeling that they had received good clinical care. This group also described feeling that they had received good aftercare, and having trust in the system.

**Table 3 Feeling confident in the system references**

Sub-themes	Number of References
Good clinical care	1,718
Good aftercare	287
Trust in the system	141
<b>Total number of references</b>	<b>2,146</b>

## Good clinical care and good aftercare

Good clinical care was represented as the treatment or operation going well or being successful, and when the patient described their care as excellent or first class (1,718 references). Good clinical care was referred to in all six free-text comment boxes relating to diagnosis, treatment, inpatient care, chemotherapy or radiotherapy



treatment and to the overall cancer care experience. Good coordination between staff and departments was also valued highly.

“The consultant and breast care nurse are all extremely knowledgeable, kind and very informative. The treatment and care I received in every department was wonderful. I can’t see any way in which it could be improved (in my opinion anyway). They seem to have ‘just got it’.”  
Female, Age 55-64, Breast Cancer

“Couldn’t have asked for better care. Every aspect of my treatment, from the operation to chemotherapy and radiotherapy. True professionals who do a fantastic job. Who also support and reassure at the most difficult time in a patient’s life.”  
Female, Age 45-54, Breast Cancer

“Standard of treatment in all areas was exceptional and very well coordinated. Seamless transition from chemotherapy, surgery, radiotherapy. All staff were professional, compassionate and respectful.”  
Female, Age 65-74, Breast Cancer

As well as clinical care, participants commented on their positive experiences of aftercare following treatment. Good aftercare included comments describing prompt advice and support when needed after treatment or operations (287 references). Patients commented on the reassurance of having regular follow-up appointments, phone calls and scans after treatment to monitor their cancer. In some cases aftercare also involved regular visits from district nurses or GPs after surgery or chemotherapy treatment, as well as counselling or support from cancer charities.

“I feel I was given the best possible care at the time and during the follow up checks, which are still on-going. This fills me with confidence that I’m being supported on a long-term basis and any reoccurrence of the cancer would be spotted early.”

Female, Age 65-74, Gynaecological Cancer

“Throughout the entire process I felt cared for and informed about progress and treatment options. Follow up care was excellent, both from care support staff, by phone call and also from cancer helpline .... Care in cancer centre was excellent.”

Female, Age 64-74, Colorectal Cancer

“Still keep in touch with hospital and doctor by phone. Hospital clinical specialist has phone and keeps in touch.”

Male, Age 65-74, Urological Cancer

## Trust in the system

A further 141 references were made by participants who expressed their trust in the health and social care system involved in cancer care. This theme was particularly prominent in comments about treatment decisions. Patients referred to being provided with clear explanations of treatment options and being treated with respect and sensitivity. They noted having complete confidence in clinical staff and trusting doctors to make the best decisions for their treatment.

“I trusted the decisions of the oncologist, the plastic surgeon and the breast cancer nurses completely. I believe the treatment was the best option for me, with the best outcome.”  
Female, Age 55-64, Breast Cancer

“I did not question what was to be done. I accepted that I was being given the best treatment for my condition. I had complete trust in the professionals.”  
Female, Age 65-74, Breast Cancer

“I felt totally confident at all times with the expertise of all the medical staff concerned. Their attitude and personal care for me was outstanding and all my questions were answered clearly and sensitively.”  
 Female, Age 65-74, Colorectal Cancer

## Processes

Fourteen per cent of all positive responses related to processes. The vast majority of these comments described processes as efficient. Other comments described patients receiving treatment quickly.

**Table 4: Positive Processes references**

Sub-themes	Number of References
Efficient processes	897
Quick treatment	219
<b>Total number of references</b>	<b>1,116</b>

## Efficient processes

There were 897 positive references to the efficiency of processes and cancer treatment. These comments related to the speed of organising tests and about the efficiency of organising treatment. Many participants commented on the efficiency of being referred for hospital treatment having been seen or diagnosed by their GP. 187 comments referred specifically to the response by the patient’s GP practice and expressed gratitude for the speed with which the GP identified their symptoms. They discussed being quickly referred for tests or being given thorough examinations which led to the identification of cancer.

“My GP acted quickly and has always been supportive.”  
 Female, Age 65-74, Breast Cancer

As well as quick referrals, 219 people commented on the speed of treatment. They mentioned experiencing very little delay between initial tests and further treatment such as chemotherapy or operations.

“From visit to GP everything was organised very quickly. There was no delays in any of the processes and referrals. Excellent treatment throughout.”  
Female, Age 65-74,  
Gynaecological Cancer

“I was enormously impressed by the speed with which I was slotted in for all the tests I needed. I started radiotherapy a few days after diagnosis and continued over the Christmas period, which I know can sometimes be difficult.”  
Female, Age 75+, Haematological Cancer

Participants described their experiences of cancer screenings and checks, with 301 respondents commenting positively and many being diagnosed during routine scans (bowel screening test, routine mammograms). Several of these comments focused on the support and information received through the screening process. Participants noted that, due to taking part in routine checks, in many cases, their cancer had been detected early, prior to experiencing symptoms.

“Found out by going for my normal mammogram. Or I would not have known, so grateful.”  
Female, Age 65-74, Breast Cancer

“It was only through the bowel screening programme that alerted me to my condition. [Name removed] was extremely succinct and matter of fact in telling me I had cancer which I liked, might not be the case for other patients.”  
Male, Age 55-64, Colorectal Cancer

“My bowel cancer was initially highlighted by the National Screening Programme. The link between this programme and my access to local cancer services was speedy and efficient.”  
Male, Age 65-74, Colorectal Cancer

A small number of comments (11 comments) related to participants being prompted by family members, media articles or doctors to get tested. This was particularly the case for those respondents who had family members who themselves had had a cancer diagnosis.

## Structures

Three per cent of all positive references related to positive structures. These comments were generally concerned with local care options, structures and environment, and transport assistance.

**Table 5: Positive Structures references**

Sub-themes	Number of References
Structures and environment	55
Local care	84
Transport assistance	74
<b>Total number of references</b>	<b>213</b>

## Structures and environment

Having treatment in a comfortable environment was an important issue for respondents (55 comments). Patients appreciated receiving treatment in a friendly and relaxed atmosphere, and staff played an important role in this. Respondents described staff as providing a friendly, calm atmosphere, whilst maintaining a professional approach to their treatment.

Being treated on a dedicated cancer ward was preferred to attending outpatient appointments on the general ward. Some participants praised the provision of accommodation for patients by [CLAN](#)<sup>5</sup>, which was invaluable for those who had to

<sup>5</sup> CLAN Cancer Support is a charity which provides support to people affected by cancer across north-east Scotland, Moray, Orkney and Shetland.

travel long distances for treatment. The availability of car parking dedicated to those receiving cancer treatment was also an important issue.

“I was given written information throughout but was left unsure of what, where and how chemotherapy was given. The oncologist described a large room with chairs which seemed impersonal and dismal but in fact I was in a bright, airy ward divided into bays with large reclining leather chairs where it was possible to chat with others or not. Perhaps photos online would have helped so that people know what to expect.”

Female, Age 55-64, Breast Cancer

“Excellent care from beginning to end. Atmosphere was relaxed, staff friendly, while also very professional.”

Female, Age 65-74, Breast Cancer

“It helped being in a breast cancer ward, rather than a general surgical ward.”

Female, Age 65-74, Breast Cancer

## Local care and transport assistance

The availability of assistance with transport to and from hospital appointments was valued by some participants (74 references). Some respondents living in remote locations greatly appreciated being able to use services provided by local charities and volunteer drivers. The importance of transport assistance was illustrated by participants who described long journeys after receiving chemotherapy or other treatments as being exhausting and uncomfortable.

As well as transport assistance, participants commented on being able to receive treatment nearer home. In some cases, patients requested their chemotherapy treatment to be administered in a different hospital to reduce the need to travel long distances.

“I was lucky enough to get patient transport to all of my appointments, this service was invaluable. The drivers were great with me and were very helpful and organised.”

Male, Age 75+, Head and Neck Cancer

“I had my chemotherapy – and also my current chemotherapy – at [hospital name]. This is much closer to home, and I am so grateful my cancer team were able to arrange this. Otherwise, I would have had to travel long distances whilst feeling nauseous and emotional.”

Female, Age 55-64, Breast Cancer

### 4.3 Negative Comments

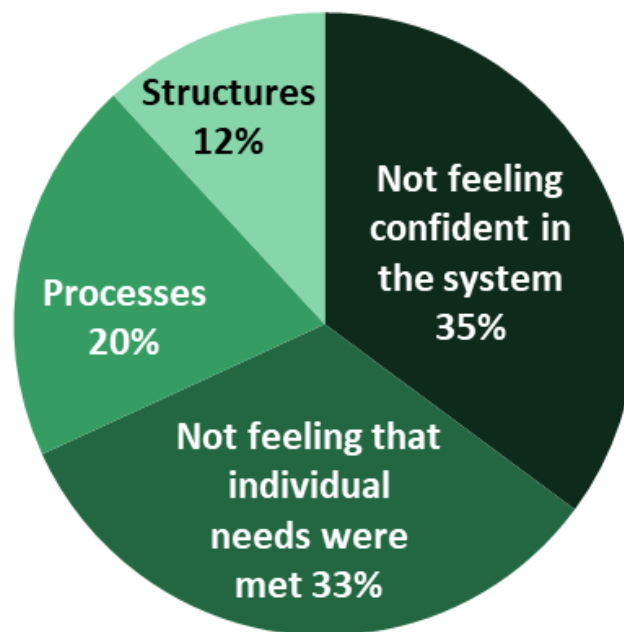
In total, there were 2,285 negative comments in the free-text boxes. As outlined earlier, participants made substantially more positive than negative comments about their experiences of cancer care. However, negative comments tended to be longer and more detailed than positive comments.

Negative comments were related to four main themes:

- Not feeling confident in the system
- Not feeling that individual needs were met
- Processes
- Structures

The proportion of the total number of references made to each of these themes across the six free-text questions was recorded and is shown in the chart below. Within each of these themes, a range of sub-themes was identified. These sub-themes are discussed in the following sections. Participants' comments often referenced more than one sub-theme. No comments were double counted within any sub-theme, however, an individual respondent may have made reference to more than one sub-theme within a single comment box.

**Figure 16: Distribution of negative references across main themes**



#### Not feeling confident in the system

Thirty five per cent of all negative comments related to patients not feeling confident in the system. This group described a range of issues, including: poor care; inadequate aftercare; difficulty getting into the system; inconsistent or inappropriate information; lack of faith in the system; and inadequate contact.

**Table 6: Not feeling confident in the system references**

Sub-themes	Number of References
Poor Care	271
Inadequate aftercare	305
Difficulty getting into the system	409
Inconsistent or inappropriate information	386
Lack of faith in the system	97
Inadequate contact	334
<b>Total number of references</b>	<b>1,802</b>

## Poor care

Across the six comment boxes, patients described a range of issues associated with feeling that they experienced poor care (271 references). These included problems with treatment, including inadequate management of side effects or pain relief. Some patients felt that poor care had led to longer recovery times and, in some instances, the need for further treatment or being readmitted to hospital. Inconsistency in care was also a concern for respondents, who highlighted different experiences of care when attending hospitals on weekends, or different hospitals for treatment.

“After surgery the pain management team failed to control my pain. I was made to feel that I was complaining of pain because I had a low threshold of pain. My GP got the pain under control when I got home.”  
Female, Age 65-74, Lung Cancer

“The post-operative care, both in the HDU and thereafter in a ward, was at best frequently insensitive and sometimes actually frightening, there was no way of addressing this. Wards need more senior and responsible staff taking a personal interest.”  
Male, Age 55-64, Colorectal Cancer

A small number of participants describe cases where they underwent unnecessary tests and were given medication for other conditions, as a result of their cancer not being initially diagnosed. Not being able to get up-to-date information or answers to specific questions about their treatment plan from nurses on the ward added to patients’ anxiety and stress during their care.



“The care I received, particularly after my operation, was not good, also prior to my operation I was prepped every day for several days and told my operation wasn’t being done. My care after my operation was poor...I really struggled to move, was in a lot of pain and felt that no-one had any time to help me in any way. When I asked for help I was always told later, but later never came. My medication ran out and it took several days to get replacement.”

Female, Age 55-64, Colorectal Cancer

“Night nursing care was poor.”  
Male, Age 55-64, Prostate Cancer

“I found hospital staff sometimes were unsure of questions about treatment, side effects and ways of dealing with (or indeed, preventing) side effects of treatment.”

Female, Age 55-64, Breast Cancer

Instances of poor care due to staff not being trained in specific procedures were also noted, particularly during inpatient treatment. There were isolated references to patients having additional health problems resulting from treatment, such as infections or side effects. Some respondents also noted that GP practices and nurses visiting the patient at home were often not prepared for patients with cancer. In some cases, this meant that respondents found it difficult to organise the correct blood tests before hospital appointments, or did not receive the correct post-operative treatment for wounds and dressings after being discharged from hospital.

## **Inadequate aftercare or support after treatment**

Some participants also described experiences of inadequate support after treatment (305 references). Issues included a lack of contact from health care professionals after being released from hospital, and being unsure who to contact for support about side effects of treatment or other post-operative concerns. Some comments described experiences of being discharged from hospital without sufficient support at home and no clear understanding of available support services. As well as the lack of clinical aftercare, a small number of comments referred to the lack of emotional support and aftercare (44 references), such as counselling. Some participants felt that they were not given sufficient mental health care after their treatment.

“I have some long term physical side effects, which impact my day to day life. I don't feel there is anything going on to support me with these. I now feel quite isolated in dealing with this. I pay for some therapies, but would like to have the opportunity to discuss my treatment options with professionals in cancer care.”

Female, Age 55-64, Breast Cancer

“I cannot emphasise enough the importance of the support which should be given in the post treatment period. Handing out booklets is not enough. Depression, for example, would appear to be quite a common after effect of cancer treatment but nobody raised this with me or my family. I sought out my own help.”

Female, Age 65-74, Breast Cancer

“I felt I was not told the long-term effects of the treatment in enough detail. Once treatment ended I felt lost and that the support I had just stopped dead. I still had many symptoms but didn't know if that was the norm,”

Female, Age 45-53, Breast Cancer

“There is not enough help given which will enable you to deal with the collateral damage / side effect of the treatment.”

Male, Age 65-74, Head and Neck Cancer

A lack of support after treatment was also noted in comments made by a small number of patients who felt they were discharged from hospital too early (22 references). These participants described leaving hospital whilst still feeling weak and suffering from treatment side effects. They describe being concerned about not being able to deal with side effects or monitor their post-operative care on their own.

“I did not feel ready to leave the hospital after my operation. One of the main reasons being I live over [number removed] miles away and was scared it was too soon and worried if I had a relapse or needed medical care.”

Female, Age 55-64, Gynaecological Cancer

“I was discharged the day after the operation – I believe that this was a day too soon. More information is required to ensure patient and family are geared up to aftercare at home. E.g. equipment etc.”

Male, Age 65-74, Prostate Cancer

## Difficulty getting into the system

A key concern expressed by patients was the difficulty they encountered getting into the system and receiving a cancer diagnosis (409 references). Some participants described attending multiple appointments with their GP practice over the course of several weeks or months before being referred to hospital for a cancer diagnosis. As well as a delay in cancer diagnosis, in some cases this resulted in misdiagnosis and treatment for different ailments. Some participants reported seeking advice from another GP or going direct to hospital after having been refused additional tests by their own GP practice.

“Symptoms were unchecked for a period of time, and blood tests would have provided some useful hints as to what was wrong with me. A&E consultant refused to even examine me, did not lay a finger on me, despite being in extreme pain. He also did not do blood test, merely sending me away to get a prescription from my GP.”

Male, Age 35-44, Haematological Cancer

“The biggest issue was that my GP did not investigate my symptoms, but only prescribed laxatives. I have since changed GP. The failure of my GP to investigate my symptoms means my cancer is more likely to diminish my life expectancy.”

Female, Age 55-64, Gynaecological Cancer

## Inconsistent or inappropriate information

Receiving incorrect or inconsistent information was a further source of concern and worry (386 references). Some patients described being told that they were receiving treatment for a different condition, only to later discover, after additional tests, that it was cancer. Many respondents commented that the change in diagnosis led to increased anxiety. Conversely, some patients commented that they had been told their cancer was more severe, or incurable, than it was later found to be.

“Before my cancer diagnosis I went to my GP twice, hospital A&E once and at a hospital appointment for a different ailment I mentioned my symptoms to the doctor I saw. On all four occasions minor ailments were diagnosed. I was first told I had cancer by a doctor at my bedside whilst I was in hospital for a biopsy. I was on my own as it was not visiting time and my bedside curtains were not closed so other patients could hear what the doctor was saying. The doctor told me in such a way that made me think they thought I already knew but I did not know before then as cancer had only been suspected.”

Female, Age 45-54, Gynaecological Cancer

“The only aspect of my care that I found unsatisfactory was in my dealings with the assigned cancer nurse where I felt there was misinformation, perhaps due to the lack of updated training / knowledge and sometimes presenting a worst case scenario as a given, rather than stating it was a worst case scenario.”

Female, Age 65-74, Breast Cancer

Some respondents described being given inconsistent information about their course of treatment or potential side effects, and in some cases, treatment was changed with little advance warning. This led to participants feeling confused and less confident about future decisions regarding their cancer care.

“Very confusing. Decision made by MDT was overturned as professional from Beatson not there. I was told radiotherapy only and when went to discuss that, it was overturned to chemotherapy and brachytherapy – I was very shocked.”

Female, Age 55-64, Gynaecological Cancer

## Lack of faith in the system

Another issue related to patients’ negative experiences of cancer care was a lack of faith in the system (97 references). Several participants described feeling that their GP or consultant could have acted more quickly to carry out or refer them for diagnostic tests. As a result, patients felt less confident that any future symptoms or deterioration in their health would be picked up and remained concerned about future monitoring processes being effective. In addition, some participants expressed a lack of trust that screening tests would pick up abnormal results. Delays in treatment or a lack of knowledge about the specific needs of a patient also contributed to a lack of confidence in the system.

“My care was complicated by the fact that the scan indicated a possibility of cancer in more than one place, but I felt there was a lack of urgency in determining the extent of cancer and arranging the necessary treatment.”

Male, Age 75+, Lung Cancer

“I arrived for my first chemotherapy unprepared. RAH did not provide necessary medication needed before chemotherapy. Was just commencing when this was discovered. At that point realised not to trust and to be vigilant. To question anything I felt uncomfortable with.”  
Female, Age 65-74, Breast Cancer

## Inadequate contact

There was concern amongst some participants about a lack of adequate contact with cancer specialists or the appropriate medical professional (334 references). Of these, 162 people specifically felt that they had not had adequate contact with their GP, before, during or after their cancer treatment. Having no contact with their surgeon or doctor after their operation was also mentioned by many respondents. Through the comments respondents expressed that they would have liked to have had an opportunity to discuss with their consultant the outcome of their treatment and any further treatment that would follow. Several mentioned that they did not know who to contact for support, had difficulty contacting cancer nurses for advice, or did not feel that they received support from their preferred healthcare professional.

“System did not allow for follow up meeting with surgeon after operation.”  
Male, Age 65-74, Prostate Cancer

“...my only real gripe is that the consultants are so busy, they never have the time to discuss how my procedure went on the day. I don't always get a copy of the report and if I ask, I'm usually told that it will be sent to my GP who will contact me. Thus far, my GP has never contacted me – it has been up to me to make an appointment to discuss the latest findings, which is strange because the GP is not a specialist, so it would make sense to discuss this with the consultant on the day on the procedure. The only communication about what to do or who to contact if I experience any complications following my procedure is on a leaflet handed to me as I leave.”

Male, Age 75+, Upper Gastrointestinal Cancer

## Not feeling that individual needs were met

Thirty three per cent of all negative comments related to patients not feeling that their individual needs were met. This group described a range of issues, including: information; poor communication; lack of information about financial support; lack of third-sector support; emotional support and responsiveness; involvement and choice; specific and unusual circumstances; and family.

**Table 7: Not feeling that individual needs were met references**

Sub-themes	Number of References
Information	690
Poor communication	419
Lack of information about financial Support	55
Lack of third-sector support	53
Emotional support and responsiveness	254
Involvement and choice	132
Specific and unusual circumstances	30
Family	59
<b>Total number of references</b>	<b>1,692</b>

### Information

Many participants commented on the amount of information they received about their treatment (690 references). Some patients talked of feeling overwhelmed by the amount of information they were given when they were first diagnosed. Often they were provided with leaflets and written information but felt it was not made clear what was relevant to their specific treatment. In some cases, participants commented on the invaluable support provided by family and friends and how they relied on them to remember details of the information presented in early appointments. Other participants felt that they did not receive enough information about their cancer type and the possible side effects, and would have appreciated a more detailed explanation of their treatment plan. This was similarly the case after treatment for some patients. Many discussed the need for more detailed information on how to manage side effects once discharged from hospital.

“There was a lot of information by way of brochures / leaflets, etc. At the time I was not sure which actions were appropriate to me. I was not sure which of the options were appropriate until I saw the consultant. There was a lot of information to take on board when decision making is potentially flawed and your mind can be overwhelmed.”  
Male, Age 65-74, Prostate Cancer

“A lot of information was given and expected to be understood immediately. More time for initial appointment.”

The way in which the information was presented was also discussed. Many patients recalled initially being given oral confirmation of their cancer and would have preferred to be given more comprehensive written information prior to attending their next appointment. This would have given them more time to come to terms with the specifics of their diagnosis before discussions of their treatment plan.

“I was told over the phone. I appreciated the fact that I didn’t have to wait for an appointment and could get the relevant bloods done at the doctors quickly (the next day). My 1<sup>st</sup> appointment with the hospital was a week later. I didn’t get the written information, referred in question 10 until that appointment.”

Female, Age 35-44, Gynaecological Cancer

“Although explanations and discussion took place, I would have liked more information written. This would have been a good way of remembering all that was discussed.”

Female, Age 65-74, Breast Cancer

## Poor communication

Many participants who commented on negative care experiences described instances of poor communication during their treatment (419 references). Of these, 157 participants commented on the poor delivery of their diagnosis. A number of participants describe being informed of their cancer abruptly and insensitively, without any prior expectation of there being cancer. Some patients were told over the phone, rather than during a face to face appointment. In a number of cases, patients mentioned that they were told of their cancer by a nurse practitioner rather than their GP or consultant, and the nurse was unable to answer detailed questions, increasing their confusion and anxiety. There were also isolated instances where patients did not feel that staff had treated them with respect or listened to their concerns.

“I was told about my cancer over the phone. No sensitivity or compassion in any way.”  
Male, Age 65-74, Colorectal Cancer

“My diagnosis was given to me by an advanced practice nurse who was unable to answer all the questions I had, only passing out printed material.”  
Male, Age 55-64, Prostate Cancer

“I do not think you should be told via a phone call that the biopsy results came back as cancer! I think something like that you should be told face to face.”  
Female, Age 35-44, Head and Neck Cancer

## Lack of information about financial support

A small number of participants discussed the lack of financial support, or the lack of information about the availability of support, for cancer patients (55 references). The lack of financial support during treatment was a major concern for some patients, and led to unnecessary extra concern and stress during treatment and recovery. Many participants noted that they had to search for support options themselves and were not proactively offered any assistance. This appeared to be a particular issue for patients who were resident in remote or rural areas and needed to travel long distances for treatment.

“During my treatment I only found out about benefits you can claim from Macmillan and Maggie’s. If people don’t use this support then there is no-one to tell you what to do. There needs to be more information given to people about benefits. I can totally understand why people get money worries and this causes more stress which they don’t need.”  
Female, Age 45-54, Breast Cancer

“There needs to be an investigation as to how treatment of folks from the outer isles is managed. I had to do almost all the journeys on my own, as funding was only offered for the one flight directly for the surgery.”  
Female, Age 45-54, Breast Cancer

## Lack of third-sector support

A small number of respondents described a lack of support from third-sector organisations (53 references). These participants commented that they received little or no support from third-sector organisations or charities, were not told about available support in their area, or felt that some organisations did not provide suitable emotional support.



The need for charities to initiate contact with patients, or maintain frequent communication, was also important to some respondents. Many patients remarked that they heard about the support available from third-sector organisations from other patients, rather than from the charities themselves. Some participants remarked that, although they had received useful information about financial and practical support from charities, third-sector organisations were not equipped to help them with the emotional or psychological effects of their cancer treatment.

“There has been a lack of communication with a support group at Maggie’s [location removed]. One should be on an email contact list and reminded of dates and times of meetings.”  
Male, Age 65-74, Upper Gastrointestinal Cancer

“Third sector organising are not equipped to help you psychologically. That would help many like me.”  
Male, Age 55-64, Colorectal Cancer

## Emotional support and responsiveness

Some participants felt that they did not receive sufficient emotional support during their cancer journey (254 references). Many of these comments referred to the lack of emotional support and compassion expressed at the time of diagnosis. These respondents were often not prepared for the possibility of a cancer diagnosis, and in many cases did not have family or friends present to help them.

“Not enough support at original diagnosis, particularly hard time in the first few weeks before treatment starts.”  
Female, Age 45-54, Breast Cancer

Responses suggested that patients’ feelings of being unsupported resulted from a lack of contact with the correct clinical profession during and after treatment. Some patients specifically mentioned not being assigned, or not being able to get adequate contact with, a clinical nurse specialist. Those that did contact their assigned cancer contact often felt that they did not have enough time to discuss the emotional effects of the treatment. The lack of knowledge of available support and third sector organisations contributed towards feelings of isolation.

A lack of support once treatment had finished meant some patients felt abandoned and isolated. Some respondents noted that it was after completion of their treatment,

and as they transition back to community care, that they particularly struggled to come to terms with their cancer diagnosis and the effects of surgery or treatments.

“I feel that when you have finished all your treatment you are just dismissed after months of going to hospital appointments and getting treatment you form a close bond with a lot of people but when treatment is finished so is the medical team which I found hard to come to terms with and still am.”

Female, Age 45-53, Breast Cancer

“I feel that after diagnosis and surgery I have had no emotional support and very much struggle with the effects, as do family.”

Female, Age 25-34, Gynaecological Cancer

## Involvement and choice

A number of participants felt that they were not involved in the decisions being made about their treatment, or were not given enough choice about the options available (132 references). Some participants described feeling that meetings to decide the course of treatment had occurred without their attendance or input and that decisions about their treatment plan had taken place before they attended their first oncology appointment. As well as not being presented with all possible treatment or reconstruction options, disagreement amongst the medical team and conflicting advice led to increased worry and confusion for patients, who often felt unable to challenge the “decisions made by the experts.” This led to some patients feeling that they needed to make decisions quickly, without a comprehensive understanding of possible side effects. However, there were also instances of participants feeling that they were given too many choices and needed further support in order to make a decision.

“Decisions had to be made instantly, on the spot, in the hospital. While I’m sure the decisions made by the hospital were correct and necessary, and of course I signed the consent form, I do not think there was the remotest comprehension on the part of the medical staff (for whom all this is a daily routine) of my state of mind and level of panic and distress. To be stared at by a whole team of medics when you are at your most vulnerable, only compounds the situation.”

Female, Age 75+, Colorectal Cancer

“The decisions were made promptly and I was told of them afterwards. Although generally for my benefit, I felt a little more consultation with me over the decisions would have helped in my understanding of the general situation.”  
Male, Age 5-64, Head and Neck Cancer

“I don’t think there is a lot of discussion. I think at consultation you are just given the facts and told what the treatment would be. The constraints of appointment times limit the time for any discussion, therefore you have to accept the outcome.”  
Female, Age 65-74, Breast Cancer

## Specific circumstances

A small number of participants who had specific individual needs or unique circumstances did not feel that these were taken into account when considering their treatment or cancer care (30 references). These participants felt that the system did not sufficiently support those with additional needs, including disabilities or dietary requirements. Some participants were concerned that existing medical conditions (e.g. weakened immune system) were not considered when they were placed in general wards or waiting rooms between appointments. Another specific concern related to patients who had a family history of cancer and requested a mastectomy be considered but were told that this was not an option.

“I have a complex medical history. I felt this was not considered before treatment. A discussion needed to happen on what the effect of chemotherapy can be to an otherwise healthy person “  
Female, Age 45-54, Breast Cancer

“I had a few infections during my chemotherapy leading me to go into hospital. I was put in a ward with the general public where it was obviously known my immune system was low and I had people coughing at either side of me which contradicted the advice given to me to stay clear of anyone who was ill.”  
Female, Age 35-44, Breast Cancer

“My previous medical conditions were not taken into account and documentation given to staff about me was not adhered to. I could not see to do the exercises from the physio and due to mental health problems unable to remember to do them, however, the leaflet was just left on my bed.”  
Male, Age 65-74, Colorectal Cancer

## Lack of support for families

A small number of participants described experiencing a lack of consideration and support for their families during their cancer treatment (59 references). One concern was not being able to have family members or friends with them during appointments, and particularly during chemotherapy treatments. This meant patients were sometimes left alone for long periods of time while waiting for procedures or during treatment, resulting in increased levels of anxiety and feelings of isolation.

“Going through cancer treatment is very scary and upsetting for the patient and the family. I’d like to have my partner with me while I was having chemotherapy. I felt very lonely, scared and overwhelmed by the other patients.”  
Female, Age 35-44, Breast Cancer

“My only criticism is that at The Beatson I was not allowed to have anyone to sit with me, except on the first occasion, as they have a space issue. The staff were very busy and it’s a very lonely feeling sitting alone in there, as I also found very few patients wanted to talk to anyone else. I noticed by contrast at The New Victoria Hospital everyone had a friend/partner sitting with them during chemotherapy.”  
Female, Age 55-64, Breast Cancer

Some participants described not being given prior warning of what was going to be discussed at their appointment. In some cases, not knowing what to expect meant that participants had children with them, when they would have arranged childcare if they had known what was going to be discussed. Participants also described difficulties in finding advice or support to help their family through their cancer treatment. The benefits of having some support in place for family members, particularly children, to help them deal with a family member’s cancer diagnosis, treatment and side effects was emphasised in several patients’ comments.

“Once terminal diagnosis is given and then to go to curative, more mental healthcare should be provided for not only patients but for family and children. I had to research and seek without for the care me and family needed.”  
Female, Age 35-44, Colorectal Cancer

“My child found it very difficult at this time and I feel it would have been useful to have had someone they could have spoken to and answered the questions they had.”  
Female, Age 55-64, Upper Gastrointestinal Cancer

## Processes

Twenty per cent of all negative comments related to the organisation of treatment and care (1,024 references). Most of these comments described issues related to waits and delays, and ineffective and unreliable administrative processes. Other issues included insufficient screening tests and fragmented care.

**Table 8: Negative Processes references**

Sub-themes	Number of References
Waits and delays	487
Ineffective and unreliable administrative processes	243
Insufficient screening tests	108
Fragmented care	186
<b>Total number of references</b>	<b>1,024</b>

### Waits and delays

Waits and delays in relation to appointments were a source of concern for many participants (487 references). Such comments appeared to be associated with experiences of ineffective administration and difficulties getting into the system. This group described experiencing delays for referrals from their GP, organising appointment dates, waiting for surgery and chemotherapy appointments and waiting for outpatient appointments. Delays in receiving test results and organising follow-up and aftercare appointments were a major source of concern for patients. In many cases, delays in treatment had led to increased anxiety, and some patients were concerned that their cancer had progressed during this time, resulting in more extensive surgery or longer treatment. Some comments also described experiences of chemotherapy appointments where patients waited several hours for treatment to begin due to delays with drugs being prepared at the clinic.

“Test results have taken a long time to be assessed and then passed to the referring doctor. Seems to have taken a long time and been long winded getting the correct information to the correct person so treatment could be started / carried on and completed (still waiting!).”

Female, Age 35-44, Haematological Cancer

“The waiting time at clinics is unacceptably long. First time I went to the oncologist I was almost an hour in the waiting room and by the time I saw him even the receptionist had gone home. This was very stressful.”

Female, Age 65-74, Breast Cancer

“The care for my breast cancer was excellent in every way, however my ongoing condition requires me to have regular checks; colonoscopies and gastroscopy and this has a very different and disorganised side of care. Both investigative procedures are regularly delayed and / or overlooked and left to the patient to pursue. This can mean the difference between survival or not as these tumours grow rapidly with this condition.”

Female, Age 65-74, Breast Cancer

### Ineffective and unreliable administrative processes

Many patients described difficulties with the administration and organisational elements of their cancer care (243 references). Problems included: delays in letters being sent to patients; problems with the organisation of appointments; and difficulties sharing of patient records between hospitals and GP practices.

Respondents expressed frustration at the lack of sufficient notice for cancelled or rearranged appointments. In some cases, patients received letters notifying them of a change to their appointment or treatment date on the day of the planned appointment, or even several days later. Participants described feeling that they were responsible for remembering when their next follow up appointment or next treatment or injection was due, because of a lack of communication from their GP or reminder letters from the hospital. This often led to patients experiencing stress and concern because they were not confident they were being monitored by the system. Similarly, some respondents mentioned chasing up test results themselves. They had often been told by clinical staff that they should receive frequent follow-up appointments or scans, but this was not followed through by administration systems. Without patient intervention, aftercare appointments were sometimes scheduled less frequently, or not at all. In some cases, follow up appointments had taken place before scans, so results could not be discussed until a much later appointment.

“There was some mix up with dates for tumour removal operation. I was to get one week of radiotherapy then the operation but when contacting the hospital to confirm operation date, they knew nothing about it. The date and the surgeon was then changed. First time meeting the surgeon was day of operation.”

Male, Age 55-64, Colorectal Cancer

“I feel that all tests, i.e. MUGA should be done before any information on treatment’s given. We had talked through the chemotherapy, visited the chemotherapy suite, went through all that chemotherapy entailed, made myself ready for chemotherapy only to be told it would not be taking place due to MUGA scans.”  
Female, Age 55-64, Breast Cancer

“A rather long time between appointments and dates were often changed and cancelled.”  
Female, Age 75+, Colorectal Cancer

For some patients, ineffective communication between hospitals and health boards was a source of great irritation. Some participants reported that their GP practice had not been informed of their diagnosis by the hospital, so were surprised to be asked to carry out specific blood tests. Some respondents also noted that records and notes had been mislaid, or not shared with their medical team in a timely manner.

“Because I was at 3 different hospital sites for assessment and surgery the communication was not always efficient. I had to keep phoning and chasing up appointments and then results. Very stressful and staff on the phone not always helpful.”  
Female, Age 55-64, Lung Cancer

“Cancer hospital had no access online to view my medical records or blood test results held at my GP practice. I had to take copies of results, which I sometimes had problems obtaining. Why can’t medical institutes not have access to these, so the surgeon can have accurate data?”  
Male, Age 55-64, Prostate Cancer

## Insufficient screening tests

Some participants commented that they would have benefitted from having more regular screening tests (108 references). Many of these participants described having no symptoms, and suggested that their cancer may have been diagnosed earlier if they had received additional blood tests or screenings. Comments also noted the need for further tests during treatment to alleviate potential side effects, as well as follow up tests post-treatment.

“The first GP I saw at my clinic should have sent me for tests sooner it wouldn’t have changed the outcome but I would have started treatment earlier.”

Male, Age 65-74, Lung Cancer

“A reaction to the chemotherapy caused ongoing medical issues, which could have been avoided by testing for this prior to treatment. I was not told about this test or offered it.”

Female, Age 55-64, Colorectal Cancer

“I would have liked to have had a follow up scan. When I self-referred I was given a scan and the news of the spread reported. I was told that routine screening was not standard and that it was up to me to pick up any signs. Bearing in mind I had phlebitis, cording, a sore shoulder and joint pain. I didn’t know how I was supposed to identify spread until it was too late.”

Female. Age 55-64, Breast Cancer

## Fragmented care

Care was sometimes defined as fragmented, involving a number of different hospitals and departments, and participants described the negative effects this had on their overall cancer care experience (186 references). For many people in this group, repeated changes in doctors and hospital departments resulted in additional stress and a lack of confidence in decisions affecting their care.

A perceived lack of communication between different medical teams was a key source of concern. Respondents expressed frustration about information not being passed between doctors, and updated records and test results not being readily available in advance of their appointments. In some cases, patients recalled doctors having no knowledge of what tests or procedures the patient had already had. This was a particularly issue in communications between GP practices and hospitals. Patients were concerned that a lack of individual ownership of their care had led to conflicting decisions about their treatment. Several respondents commented that they would have preferred to see the same nurse or consultant all the way through their treatment as they felt that this would have provided them with greater reassurance about the decisions being made.



“I felt there could have been more communication amongst the various teams involved with my care.”  
Male, Age 75+, Colorectal Cancer

“The information varied depending on the consultant and I never saw the same person twice.”  
Female, Age 45-54, Breast Cancer

“The biggest choice between radiotherapy, hormones and surgery was not explained in a single clear conversation. I went to a consultant only to discover they did not do the surgery, so I had to go back in the queue to see the correct surgeon. Then I had to make a separate appointment to discuss radiotherapy and hormones. This was not joined-up thinking and I felt the decisions were left too much to me.”  
Male, Age 55-64, Prostate Cancer

## Structures

Twelve per cent of all negative comments were related to structural issues (609 references). Respondents described a broad range of structural issues, including: the care environment; lack of support; staffing levels; privacy; transport; and local facilities.

**Table 9: Negative Structures references**

Sub-themes	Number of References
Unsuitable or uncomfortable environment	151
Generalised lack of support	96
Staffing levels	105
Privacy	48
Transport	119
Lack of local care or support facilities	90
<b>Total number of references</b>	<b>609</b>

### General lack of support

A small number of patients (96 references) described experiencing a general lack of support. This group of patients felt that there had been little or no organised support in their cancer care or treatment. However, these comments were very general and did not specify the form of support which the participants found lacking. They often referred to being “alone” in the process, little or no support being offered, and not being provided with information about available support.

“Very little support offered.”  
Male, Age 75+,  
Prostate Cancer

“No help really – Even though my GP practice were aware of my condition and that I was sole carer for my relative – Social Services were aware of this as well.”  
Male, Age 65-74, Prostate Cancer

## Unsuitable or uncomfortable environment

Across all of the free text boxes, there were a number of references to aspects of the care environment being unsuitable or uncomfortable (151 references). Such issues were primarily related to inpatient experiences, including: unsuitable rooms; a lack of available beds on the ward; food or specific dietary requirements; noise levels; and poor hygiene.

Patients receiving inpatient treatment commented on the lack of available beds in the ward and the resulting delays in being admitted during their hospital stay. Patients described instances of being moved between several different wards over the course of a day. Several patients commented negatively on being asked to wait in the public waiting room in hospital gowns before treatment. This was also experienced by some patients during outpatient treatment. As well as being uncomfortable, they described feeling upset, claustrophobic and anxious while waiting in the public waiting room during outpatient treatments.

“Although I knew I was having the operation, I wasn’t aware of the process as an outpatient. I didn’t know I would have to get changed in a room and then go in a hospital gown down a public corridor to the breast clinic to have the wire put through the cancer. How painful that would be, then go back to sit in the waiting room staring at other women as nervous as me. I would have taken a housecoat to wear. The long wait behind a curtain outside the operating theatre gave me a migraine due to the bright lights.”  
Female, Age 55-64, Breast Cancer

“I spent a lot of time in hospital this year and was aware of staff shortages and the shortage of bed and for several admissions I needed to be admitted to different wards. At times it was a juggle for staff to get me back to the specialist ward for the treatment.”

Female, Age 55-64, Haematological Cancer

Other comments highlighted variability in the standard of food provided, with some patients expressing concern about the lack of variety of food suitable for different dietary requirements. Further comments described hygiene issues in wards, broken fixtures in rooms, and problems with heating. Excessive noise was also an issue. Some patients felt that noise levels on the ward, particularly during the night, impacted negatively on their stay in hospital. As well as noise during the night, some patients had experienced excessive noise related to there being a large number of visitors to the ward and doctors having consultations in the ward.

“Hospitals are too much regime, like getting the proper rest, with all the noise going on, is impossible. Ward nurses are very uncaring and can't be bothered most of the time.”

Male, Age 55-64, Upper Gastrointestinal Cancer

## Staffing levels

References to insufficient staffing levels were made at all stages of the cancer journey (105 references), but were most notable in relation to inpatient experiences. In some cases, this was related to a lack of specialised staff or a dedicated cancer ward, particularly in rural hospitals. In other cases, a lack of staff on duty meant that patients had been unable to talk directly to consultants or surgeons, or receive answers to their questions. This group described having insufficient time to ask questions, not feeling listened to, and feeling rushed due to having short appointments. As well as hospital staff, respondents commented that it could be difficult to get support via the out of hours emergency number as it was frequently busy or, in some cases, left unanswered.

“A few days after I discovered a lump I made an appointment. Dentist thought nothing to worry about. A few weeks later was my normal check-up. They said lump was bigger and would refer me to The Borders General Hospital. After a month I telephoned my dentist to say I had not received an appointment. On checking they let me know The Borders General Hospital did not have a surgeon, so it was several months until I had a biopsy.”

Male, Age 65-74, Head and Neck Cancer

“Coming from a rural area, being hospitalised over a weekend was chronic, as literally no staff to make any decisions. At that time, I felt desperate for answers and had to display my discontent for action to be taken and information shared.”

Female, Age 35-44, Breast Cancer

Some patients felt that wards were understaffed and had too many patients in their care, particularly at night. This group discussed the long shifts worked by nursing staff and the detrimental effect this has on patient care. Several respondents commented that nurses had appeared very tired and were not able to provide the necessary attention to individual patients during their hospital stay.

“There are so many people with cancer that the wards are very busy, so staff cannot spend much time with you, as there are others they must see. At the end of their 12 hour shift the nurses were very tired, so did what was necessary and went. 12 hour shifts are an accountants way of cutting the number of staff and so costs, but it is detrimental to the care of patients.”

Male, Age 55-64, Haematological Cancer

“When phoning the out of hours emergency number the line was always busy, or no-one would reply. When they did reply they were very professional. ON this note this service looks like it’s undermanned,”

Female, Age 45-54, Breast Cancer

## Lack of privacy

A small number of participants described occasions when they had experienced a lack of privacy in hospital (48 references), particularly when receiving their cancer diagnosis and during inpatient stays in hospital. This group described feeling uncomfortable about receiving their diagnosis whilst other people were in the same room, or where only a curtain separated them from other patients in the ward. Some respondents also commented that they felt it was insensitive to conduct appointments or counselling interviews in public areas, where details could be overheard by other patients or staff.

“...was taken through an assessment in a small room with phones ringing and through the assessment an additional member of staff came into the room to do their work. Not an appropriate place to conduct sensitive personal information. Very disappointed in this.”

Female, Age 55-64, Breast Cancer

“When I attended for scan results the breast care nurse always comes to speak to me in the waiting room. I’m not comfortable with this as other patients are close by – they hear us and I hear them.”

Female, Age 45-54, Breast Cancer

## Transport

A number of patients had experienced difficulties in relation to transport to and from care settings (119 references), including: car parking; costs; and a lack of availability of transport assistance.

The availability and cost of car parking was a particular source of frustration for some patients. This group noted that they had sometimes been late for appointments, or family members had been unable to join them at appointments, due to being unable to find a parking space. Results from the quantitative analysis of the 2018 survey noted that seventeen per cent of respondents found it quite or very difficult to travel to their cancer care appointments.

“Regarding travel – easy because I had a car and public transport is virtually non-existent, but then very difficult as the parking is horrendous. I was in a position where I could get dropped off, considerably reducing the stress of getting to appointment times.”

Female, Age 55-64, Breast Cancer

A small number of comments highlighted particular issues in relation to transport for people who lived in remote or rural areas. Some respondents noted that the lack of availability of public transport or flights meant that they had needed to arrange overnight accommodation at their own expense. Several patients reported that they relied on family members to drive them to and from appointments because they felt

“I had to travel and stay in [location removed] as there were no flights which connected to the ferries which would allow me to go home, even at weekends. I was not given funding for this.”

Female, Age 45-54, Breast Cancer

unable to cope with multiple or long journeys on public transport after chemotherapy and other treatment.

## Lack of local care or support facilities

Respondents also described a range of issues which were related to a lack of local care or support facilities (90 references). The data suggests that there were particular issues for people who lived in remote or rural areas, and some respondents described having to undertake long journeys for treatment, often several times a week. A small number of people reported that they had had to stay away from home, in order to be nearer the hospital and had felt isolated because they did not have family and friends nearby. Some respondents had been unable to receive treatment at the hospital closest to their home, often due to a lack of specialists or equipment.

“Radiotherapy and chemotherapy should be local hospital. I myself travelled several miles each day to lie on a machine for minutes based in one main location is a bad idea. To have sick people, some in pain, travelling loads of miles is ridiculous. My local hospital is a few miles away, not several miles.”

Male, Age 65-74, Prostate Cancer

Some patients reported that particular support services were not available in their local area, including: counselling; support for cancer patients with young families; suitable aftercare; or peer support. Others commented that they had been unable to use the facilities, or access the services, of third-sector organisations as often as they would have liked because they lived some distance from the treatment clinics.

“Could not have got through my cancer experience without the constant help from my clinical support specialist. Lack of support locally for people with cancer with a family.”

Female, Age 35-44, Haematological Cancer

“It would be helpful to meet up with cancer patients nearby where I live, even just for a coffee. Most places are further away.”

Female, Age 45-54, Lung Cancer

## 4.4 Neutral Comments

A total of 287 comments were coded as Neutral. The majority of these comments referred to patients' experiences of patient led peer support and support they received from family and friends during their cancer journey.

**Table 10: Neutral references**

Sub-themes	Number of References
Neutral / okay care	17
Patient led peer support	58
Support from family and friends	212
<b>Total number of references</b>	<b>287</b>

The small number of comments (17 references) within the sub theme 'Neutral / okay care' referred to "okay care" or care being "satisfactory", but did not provide additional details about their experience.

### Patient led peer support

Patient discussed their experiences of receiving support from peer led support groups and informal support from other patients (58 references). Many of those who commented discussed how having the opportunity to talk with others who had undergone similar treatment was both helpful and encouraging. Patients were able to discuss experiences of treatments, side effects and recovery and provide mutual support. A large proportion of the references made referred specifically to support received through informal meetings with other patients on the ward or past cancer patients. Online cancer forums and social media groups were also mentioned as sources of support and paths through which participants contacted fellow patients and maintained social contacts after treatment.

"Having never undergone major surgery it was a shock to experience the after effects during recovery. Although the hospital staff talk about the operation and post-operative recovery I was not fully prepared, but realised that I never would be. Talking to people who had already experienced this was the best help."  
Male, Age 55-64, Prostate Cancer

"The staff at Beatson are so attentive and friendly, it is not a sad place to come but quite the opposite and you meet people like you and you can discuss what is going on and share ways of coping with some of the side effects."  
Female, Age 45-54, Breast Cancer

“Much as the hospital staff, nurses etc. did to help with informing me of all options and possible side effects, it was meeting someone who had gone through the exact same treatment a number of years previously who really put my mind at rest.”

Male, Age 65-74, Prostate Cancer

There were also references to peer support which occurred in formal support group settings established through NHS and cancer charities. Such groups provided dedicated time and support for patients to ask questions and receive information and answers to questions about their cancer journey and wellbeing

“In Glasgow Royal there is a group who meet (all post-op). They will talk and answer questions, hearing them talk and knowing that it should be possible to talk after the operation is really good and very encouraging when you talk with them.”

Male, Age 55-64, Head and Neck Cancer

“The staff were amazing. They helped me come to terms with my condition and what effects it would have on my life. They gave me time to digest things fully and involved my family as per my request.”

Female, Age 55-64, Urological Cancer

“Maggie’s Cancer Unit, in Aberdeen. They had a six week workshop for people with or had prostate cancer. Around my time of operation, which had discussion groups, diet and exercise, meditation therapy, which helped me understand and copy. They still have monthly group classes.”

Male, Age 65-74, Prostate Cancer



“What I found most difficult was the emotional and psychological effects after treatment finished. I was not prepared for how difficult these could be and I am so grateful for the ‘Moving On’ course which was run by NHS and breast cancer care.

The information, support and professional guidance provided, as well as the opportunity to talk openly about feelings and concerns with other[s] experiencing similar issues, was invaluable. Thank you.”

Female, Age 55-64, Breast Cancer

## Support from family and friends

A total of 212 references were made by patients discussing the support they received from family and friends across all aspects of their cancer journey.

This support included emotional support and encouragement from friends and relatives at time of diagnosis and throughout their cancer treatment. Many participants commented on how helpful they found it to have relatives present during their cancer diagnosis as they often describe feeling overwhelmed and unable to take in details of their cancer during their first appointments.

“I found it all too much to take in. If my relative was not with me I would have found it all too much to take in.”

Female, Age 55-64, Colorectal / Lower Gastrointestinal Cancer

“Family and friends helped to advise and talk over options.”

Male, Age 75+, Haematological Cancer

“Emotional and psychological support was mainly provided by my relatives, family and friends.”

Male, Age 65-74, Haematological Cancer

“Because of my age, hearing and sight difficulties, I relied on family members to explain my condition. They accompanied me to my hospital visits.”

Female, Age 75+, Gynaecological Cancer

They also valued being able to discuss treatment options with close family and friends and receive advice and support from friends or relatives who had also undergone treatment. A small number of participants noted the benefit of family being present during appointments due to medical conditions that made it difficult to take in all details and information during their appointments.

In many cases comments mentioned family and friends providing travel assistance to appointments.

“My spouse was very supportive throughout. They generally drove me to my hospital appointments, partly because parking is very difficult and they could drop me and find a place to park, and joined me with the relevant clinician. So they [were] well aware of all aspects of my treatment and care.”  
Male, Age 65-74, Colorectal Cancer

## 5. Discussion

The Scottish Cancer Patient Experience Survey asks patients about their experience of cancer care and the support they received, from diagnosis through treatment onto aftercare. The inclusion of open ended questions, using free text comment boxes, enables respondents to provide more personal and reflective detail about their individual cancer care journey, and provides valuable insight into the experiences of cancer patients in Scotland. This is the second survey of cancer patients in Scotland which has offered respondents the option to provide free text comments in addition to the closed questions which are detailed in [Scottish Cancer Patient Experience Survey 2018](#)<sup>6</sup>. The free text comments provide valuable insights into the experiences of patients throughout their cancer journey.

In total, 3,315 people (66 per cent of all respondents) left at least one comment in the survey. The total number of comments was 9,320, and there were almost twice as many positive as negative comments (4,176 positive comments compared to 2,285 negative comments). Despite there being a greater number of positive comments, the breadth and detail of negative comments has led to greater discussion of negative themes in this report. In addition, the large volume of data meant that positive and negative comments were analysed separately, but in reality, patients' narratives suggested that experiences tended to be a mix of both.

Analysis of the free text responses highlights various topics which patients had chosen to comment on about different stages of the cancer care journey. Each of the six comment boxes asked about different stages, and there were more positive than negative comments at every stage. Almost a quarter (23%) of all comments were made in comment box 1, which specifically asked respondents about the lead-up to their cancer diagnosis, or the way they had found out that they had cancer, which suggests that this was a particularly important aspect of the cancer care journey. Furthermore, this comment box had the most mixed responses, with an almost equal proportion of positive (32%) and negative (30%) comments, suggesting that experiences at the initial stage of the cancer journey had been highly variable. In contrast, people made substantially more positive (62%) than negative (17%)

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<sup>6</sup> <https://www.gov.scot/publications/scottish-cancer-patient-experience-survey-2018-national-report/>

comments in comment box 4, which specifically asked respondents about the care they had received when they were in hospital for cancer care.

Overall, this analysis suggests that care and support, and information and communication were key issues for patients across the cancer care journey. The comments provided by patients highlight many examples of good care, particularly in relation to hospital in-patient care (comment box 4) and other care and support, including GP and third-sector (comment box 5). Importantly, they also highlight areas for improvement, most notably in relation to how medical staff had communicated their diagnosis to the patient and the lead up to diagnosis (comment box 1), as many patients had experienced difficulty in accessing the system, poor communication and information, and waits and delays.

There are several limitations, as well as strengths, in this analysis. The comments reflect the views of survey respondents who chose to provide further information about their experiences in the free text comments boxes, and therefore cannot be inferred to the wider population of cancer patients. Socio-demographic and clinical characteristics have not been included in the analysis, and are therefore not reflected in the findings. In particular, it should be noted that there is a risk of an inherent bias towards particular groups in free-text responses, including people who are more literate, have English as a first language, and who do not have learning disabilities. Notwithstanding these limitations, the analysis of free text comments provides deeper insight into patients' experiences of cancer care in Scotland and enhances the usability and relevance of the quantitative survey results.

## Appendix 1: Survey participant demographics

Respondent Characteristics	Left at least one comment		All respondents	
	Number of respondents	Percentage	Number of Respondents	Percentage
<b>Age</b>				
16-34	39	1.2	59	1.2
35-44	121	3.7	172	3.4
45-54	388	11.8	551	11.0
55-64	792	23.9	1,205	24.1
65-74	1,199	36.2	1,789	35.8
Age 75+	776	23.4	1,225	24.5
<b>Gender</b>				
Female	1,866	56	2,716	54
Male	1,449	44	2,285	46
<b>Sexual Orientation</b>				
Heterosexual/Straight	3,040	92	4,548	96
Bisexual, Gay or Lesbian, or Other	265	8	187	4
<b>Ethnic Origin</b>				
White	3,212	97	4,856	99
All other ethnic origins	103	3	55	1
<b>Employment Status</b>				
Employed (full or part time)	711	22	1,035	21
Self-employed (full or part time)	130	4	212	4
In full-time education or training	12	0	16	0
Unemployed/looking for work	25	1	44	1
Don't work due to cancer	145	5	220	5
Don't work due to another illness or disability	106	3	172	4
Retired	2,023	63	3,071	64
Other	38	1	65	1
<b>SIMD quintile</b>				
1 = most deprived	465	14	772	15
2	568	17	931	19
3	703	21	1,059	21
4	785	24	1,137	23
5 = least deprived	793	24	1,102	22
<b>Co-morbidities</b>				
Deafness or severe hearing impairment	441	11	698	12
Blindness or severe vision impairment	94	2	139	2

Chronic pain lasting at least 3 months	495	13	693	12
Physical disability	334	9	476	8
Learning disability	13	0	21	0
Mental health condition	168	4	232	4
Another long-term condition	697	18	1,000	18
None of the above	1,601	43	2,440	43
<b>Urban Rural classification</b>				
Large Urban Areas	1,016	31	1,518	30
Other Urban Areas	1,114	34	1,685	34
Accessible Small Towns	330	10	508	10
Remote Small Towns	115	3	181	4
Accessible Rural	467	14	691	14
Remote Rural	272	8	418	8
<b>Tumour Group</b>				
Brain/Central Nervous System	21	1	36	1
Breast	812	25	1,210	24
Colorectal/Lower Gastrointestinal	513	15	748	15
Gynaecological	284	9	418	8
Haematological	341	10	494	10
Head and Neck	194	6	301	6
Lung	212	6	326	7
Prostate	444	13	694	14
Sarcoma	17	1	26	1
Skin	97	3	158	3
Upper Gastrointestinal	114	3	193	3.9
Urological	252	8	381	7.6
Other / Tumour Group Unknown	14	0	16	0

## Appendix 2: Summary of Free-text Responses

Comment Box		Total	Positive	Negative	Positive / Negative	Neutral	Factual	Miscellaneous
<i>Is there anything else you would like to tell us about...</i>								
1	The lead-up to your cancer diagnosis, or the way you found out you had cancer	<b>2,160</b>	<b>695</b> 32%	<b>652</b> 30%	<b>239</b> 11%	<b>480</b> 22%	<b>87</b> 3%	<b>7</b> 0%
2	The way decisions were made about your treatment	<b>1,198</b>	<b>545</b> 45%	<b>283</b> 24%	<b>99</b> 8%	<b>184</b> 15%	<b>79</b> 7%	<b>8</b> 1%
3	Your operation / radiotherapy / chemotherapy treatment	<b>1,485</b>	<b>600</b> 40%	<b>337</b> 23%	<b>111</b> 7%	<b>375</b> 25%	<b>54</b> 4%	<b>8</b> 1%
4	The care you received when you were in hospital for cancer care	<b>1,574</b>	<b>976</b> 62%	<b>270</b> 17%	<b>162</b> 10%	<b>104</b> 7%	<b>45</b> 3%	<b>17</b> 1%
5	Any other support you received during your cancer care, including from your GP Practice and third sector organisations	<b>1,364</b>	<b>712</b> 52%	<b>307</b> 23%	<b>196</b> 14%	<b>74</b> 5%	<b>68</b> 5%	<b>7</b> 1%
6	Your experience of cancer care	<b>1,539</b>	<b>648</b> 42%	<b>436</b> 28%	<b>298</b> 19%	<b>99</b> 6%	<b>41</b> 3%	<b>17</b> 1%
<b>Total</b>		<b>9,320</b>	<b>4,176</b> 45%	<b>2,285</b> 25%	<b>1,105</b> 12%	<b>374</b> 4%	<b>1,316</b> 14%	<b>64</b> 1%



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