



Scottish Cancer Patient Experience Survey 2015/16: Analysis of the Free-Text Comments

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Contents

Acknowledgements	6
Executive Summary	7
Introduction	7
Methods	7
Findings	7
Positive comments.....	7
Negative comments	8
Introduction	10
Methods	11
Design and Participants.....	11
Data Analysis.....	15
Results	16
Positive Comments.....	16
Information	17
Efficient Processes	17
Good Support	18
Good Clinical Care.....	19
Trust In the System.....	20
Negative Comments	21
Not feeling confident within the system	23
Not feeling that individual needs were met.....	28
Structures	32
Processes	35
Analysis of Individual Comment Boxes	37
The lead up to diagnosis and finding out what was wrong with you (Comment Box 1)	37
Decisions about treatment (Comment Box 2).....	39
Support (Comment Box 3).....	41
Operation or overnight stay in hospital (Comment Box 4).....	43
Day patient/outpatient care (Comment Box 5)	45
Chemotherapy/radiotherapy treatment (Comment Box 6).....	47
Experience of cancer care (Comment Box 7).....	49
Discussion	51
Strengths and Limitations	52

Ideas for future consideration 53

Conclusions 54

References 55

Appendix A Members of Survey Steering Group 56

Appendix B Data analysis process 57

Appendix C Overview of Comments..... 59

Appendix D Definitions of Negative Sub Themes 60

List of Tables

Table 1: Comment Boxes	11
Table 2: Demographic description of all respondents and those that left at least one comment	12
Table 3: Summary of the themes and sub-themes	22

List of Figures

Figure 1: Positive aspects of care (number of comments)	17
Figure 2: Negative Aspects of Care.....	21
Figure 3 Positive subthemes for Comment Box 1 – Lead up to diagnosis.....	37
Figure 4 Negative subthemes for Comment Box 1 - Lead up to diagnosis	38
Figure 5 Positive subthemes for Comment Box 2 – The way decisions were made about treatment	39
Figure 6 Negative subthemes for Comment Box 2 - The way decisions were made about treatment	40
Figure 7 Positive subthemes for Comment Box 3 – The support you received	41
Figure 8 Negative subthemes for Comment Box 3 - The support you received.....	42
Figure 9 Positive subthemes for Comment Box 4 – The care you received when you had an operation or stayed overnight in hospital	43
Figure 10 Negative subthemes for Comment Box 4 - The care you received when you had an operation or stayed overnight in hospital	44
Figure 11 Positive subthemes for Comment Box 5 – The day patient/outpatient care you received	45
Figure 12 Negative subthemes for Comment Box 5 - The day patient/outpatient care you received	46
Figure 13 Positive subthemes for Comment Box 6 – Chemotherapy/Radiotherapy treatment.....	47
Figure 14 Negative subthemes for Comment Box 6 - Chemotherapy/ Radiotherapy treatment.....	48
Figure 15 Positive subthemes for Comment Box 7 – Experience of cancer care ...	49
Figure 16 Negative subthemes for Comment Box 7 - Experience of cancer care ..	50

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Executive Summary

Introduction

This report presents the results and analysis of free-text comments provided in Scotland's first Cancer Patient Experience Survey (SCPES). Of the 4,835 patients who took part, 2,663 (55%) left at least one free-text comment. The survey included seven free-text comment boxes relating to different aspects of cancer treatment, from the lead up to diagnosis, to the overall experience of cancer care. In total, 6,961 comments were made by participants.

Methods

Comments were analysed by a team of independent researchers, using thematic analysis to identify common themes in the responses. Analysis first identified the main positive and negative issues which participants felt influenced their experience of cancer care. Neutral/factual or miscellaneous comments were also identified. The next level of analysis involved assigning codes (arising from the data) to all comments, comparing and contrasting these codes across the data to ensure consistency and reliability. Codes were organised into similar themes, and finally, a mapping exercise was carried out to identify core over-arching themes.

Findings

On the whole, participants made more positive than negative comments (a ratio of 1:0.78). Positive comments tended to be shorter, more general and less detailed and specific than negative comments. This is a trend which has also been noted in the English and Welsh cancer experience surveys. Due to the large volume of data, positive and negative comments were analysed separately, imposing a false dichotomy between positive and negative experiences. In reality, participants had variable experiences, not overwhelmingly negative. Whilst the report devotes more space to negative comments and themes, this is a reflection of the *detail* of the negative comments made by participants rather than a statement of the balance between negative and positive comments.

Positive comments

Several distinct themes emerged from the analysis of the positive comments. Many patients described a positive experience overall, and particularly valued clear information, speedy and efficient processes, good support, good clinical care and feeling that they could put trust in the system.

The most common positive themes related to patients receiving good support and clear, detailed information. Patients particularly appreciated information that was delivered sensitively and gave them a clear idea of what to expect.

Where patients commented on the support provided, they tended to describe caring, kind, professional and approachable staff. Many comments related to receiving support from clinical nurse specialists or other nurses, as well as

charities. However, many participants remarked that they had only heard about the support available from charities through word of mouth from other patients.

Negative comments

Analysis of the negative comments indicated that there were significant issues which had impacted on some aspects of patients' care. Analysis of the data identified two key aspects of experience that were critically important (i) not feeling confident within the system and (ii) not feeling that individual needs were met. Beyond these two aspects, participants also described underlying issues with the system and the organisation of services which contributed to poorer experiences in both of these areas, these are described by the following themes (i) structures – the way services and environments are set up; and (ii) processes – the manner in which tasks are carried out.

Not feeling confident within the system

Participants described a range of circumstances which led to them not feeling confident within the health care system. The most common issue which affected patients' confidence was receiving poor care during treatment in the form of inadequate management of pain and side effects, exposure to infection, problems with treatment, or being cared for by staff who did not have sufficient knowledge of cancer. Many participants also did not feel confident if they received inadequate aftercare, with no care plan or point of contact for their care after treatment had ended.

Other issues which affected patients' feelings of confidence included: difficulty getting into the system, receiving inconsistent or inappropriate information, losing faith in the system, and inadequate contact with clinicians. Participants made comments about not feeling confident when they felt they could not trust that they were receiving the best possible care, when they felt doubt that the system would identify if their health was worsening, or when they felt that the system had caused their health to worsen.

Not feeling that individual needs were met

A major issue for participants was feeling that they were not being treated as an individual, with patients feeling isolated and alone within the system of care. Factors which contributed to patients feeling this way included poor communication, lack of involvement in decision making, lack of information and poor emotional support. Some participants also felt their family situation or particular individual circumstances were not adequately accounted for in their care. Patients all have their own individual characteristics which affect how they cope with and respond to treatment, and the participants in this survey highlighted how much they would like these characteristics to be recognised and taken into account by the people providing their care.

Structures

Some participants felt that issues with the hospital environment, transport, staffing levels and lack of privacy had contributed to having a worse cancer experience. Problems with the way services were structured caused some patients significant stress and anxiety, and also had a knock on impact on patients' feelings of confidence and being treated as an individual.

Processes

Participants commented on the impact that NHS processes had on their cancer experience. Participants felt that administration problems, and long waits and delays impacted on their care, increasing anxiety, and reducing confidence. The way care was organised, often across teams, departments and hospitals, combined with unreliable record systems left patients feeling that their care had been fragmented and that they did not have continuity of care.

Particular problem with the lead up to diagnosis

Analysis of the responses to the different comment boxes in the survey showed that participants were less happy with the lead up to diagnosis than at any other point in their treatment. The main issues for participants in the lead up to diagnosis were experiencing long waits and delays, having difficulty getting into the system, and poor communication. Many participants had experienced delays when they first experienced symptoms, due to their GP not recognising or organising testing of symptoms. This often caused participants to feel that they were not being listened to.

Introduction

Patient experience is recognised as a key marker of the quality of health care and is central to the Scottish Government's Quality Strategy. Understanding the experiences of people with cancer is increasingly important as cancer care and its treatment become more complex and the number of people living with and beyond cancer rises year on year (Maddams, Utleby, Møller, 2012).

This is the first time a Cancer Patient Experience Survey has been conducted in Scotland. Measuring patients' experiences of their diagnosis, care and treatment is vital if we are to drive improvements in cancer services across the Nation. The data gathered from the Scottish Cancer Patient Experience Survey will also help NHS Boards, Cancer Centres and Cancer Networks to understand the needs and priorities of patients within their own areas, as well as to compare against all Scotland results and those of other UK countries in so far as the methods used are comparable.

The quantitative results of the NHS Scotland Cancer Patient Experience Survey highlight that the majority of patients have a positive experience of care overall, and that many aspects of care provision are working well. The results also draw attention to particular areas of care which are less positive and require service improvement. However, the data generated from structured questions - the questions limited to multiple choice options - within the survey can only provide an overview of the issues that matter most to patients undergoing cancer treatment and care. It is increasingly recognised that data from free-text comments provides deeper and more detailed insights into patients' experiences, and that rigorous analysis of a large number of free-text comments can reveal aspects of care that are particularly important as well as those which affect people with specific needs and circumstances.

During the development phase of the Scottish Cancer Patient Experience Survey, the Steering Group endorsed the value of patients' own words to describe their experiences of care and made a decision to increase the number of free-text boxes that had been provided in surveys conducted in England, Wales and Northern Ireland, from three to seven. Rather than just ask patients what was good about their care, what could be improved, and whether they had any other comments to make, we chose to offer a free-text box at the end of each section of the questionnaire. By doing this, we hoped that patients would feel able to comment about particular stages of their cancer diagnosis, treatment and care, so that we could learn lessons for service improvement that were truly based on patients' own experiences.

Methods

Design and Participants

This report relates to the analysis of seven free-text comment boxes embedded in the NHS Scotland Cancer Patient Experience Survey. Comments boxes were placed at the end of each main topic section of the survey, to enable participants to add any further information about the issue covered in the preceding section. Table 1 shows the question asked before each comment box, and details the main topics of the preceding sections in the questionnaire.

Table 1: Comment Boxes

	Question Topic: Is there anything else you would like to tell us about...	Preceding Questionnaire Section Headings
Comment Box 1	The lead-up to your cancer diagnosis, or the way you found out you had cancer	Seeing your GP, Diagnostic Tests, Finding out what was wrong with you
Comment Box 2	The way decisions were made about your treatment	Deciding the best treatment for you
Comment Box 3	The support you received (including from a clinical nurse specialist)	Clinical Nurse Specialist, Support for people with cancer
Comment Box 4	The care you received when you had an operation or stayed overnight in hospital	Operations, Hospital care as an inpatient
Comment Box 5	The day patient/outpatient care you received	Hospital care as a day patient/outpatient
Comment Box 6	Your chemotherapy/radiotherapy treatment	Radiotherapy and chemotherapy
Comment Box 7	Your experiences of cancer care	Home care and support, Care from your General Practice, Your overall NHS Care

In total, 4,835 cancer patients responded to the survey, and of those, 2,663 participants (55%) left at least one free-text comment. Overall, 6,961 comments were left by those 2,663 participants across the seven comments boxes. The comment boxes which generated the most comments were Comment Box 1 – lead up to diagnosis (1,673 comments), Comment Box 4 – care when you had an operation or stayed overnight in hospital (1,120 comments) and Comment Box 7 – experiences of cancer care (1,075 comments). Comment Box 6 – chemotherapy/radiotherapy treatment, received the fewest number of comments (626 comments), likely due to the fact that 50% of respondents said they didn't receive radiotherapy, and 51% said they hadn't had chemotherapy.

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. Socio-demographic and clinical data were anonymised and given an identifier which could be linked to comments, prior to analysis.

The socio-demographic and clinical characteristics of all participants and those who left at least one comment are described in Table 2. These figures suggest there were no major differences between those who left a free-text comment and those who did not.

Table 2: Demographic description of all respondents and those that left at least one comment

Respondent Characteristics	Left at least one comment		All respondents	
	Number of respondents	Percentage	Number of Respondents	Percentage
Age				
16 – 34	47	2	85	2
35 – 44	130	5	182	4
45 – 54	369	14	610	13
55 – 64	649	25	1,136	24
65 – 74	864	34	1,630	35
Age 75+	512	20	998	22
Gender				
Female	1,520	59	2,659	57
Male	1,072	41	2,045	43
Sexual Orientation				
Heterosexual	2,517	99	4,545	99
Bisexual, Gay or Lesbian, or Other	27	1	47	1

Respondent Characteristics	Left at least one comment		All respondents	
	Number of respondents	Percentage	Number of Respondents	Percentage
Ethnic Origin				
White	2,558	99	4,635	99
All other ethnic origins	29	1	62	1
Employment Status				
Don't work due to illness or disability	227	9	383	8
Other	42	2	89	2
Retired	1,568	60	2,931	62
Unemployed/Looking for Work	21	1	43	1
Work Full Time / In full time education or training	458	18	805	17
Work Part Time	289	11	481	10
SIMD quintile (2012)				
1=most deprived	327	13	708	16
2	453	18	804	18
3	530	21	911	20
4	572	23	1,004	22
5=least deprived	644	25	1,079	24
Urban Rural classification (13/14)				
Large Urban Areas	795	32	1,425	32
Other Urban Areas	847	34	1,550	34
Accessible Small Towns	273	11	480	11
Remote Small Towns	96	4	165	4
Accessible Rural	327	13	554	12
Remote Rural	188	7	332	7
Time since first treated for cancer				
Less than 1 year	130	5	273	6
1 to 5 years	2,391	94	4,324	93
More than 5 years	35	1	60	1

Respondent Characteristics	Left at least one comment		All respondents	
	Number of respondents	Percentage	Number of Respondents	Percentage
Current cancer status				
My cancer has been taken out/treated without any sign of further problem	1,669	80	2,866	81
My cancer has been taken out/treated without any sign of further problem but has since come back	132	6	175	5
None of the above apply to my type of cancer	287	14	479	14
Had cancer spread at time of diagnosis				
Yes	360	15	613	14
No	2,055	85	3,789	86
Co-morbidities				
Deafness or severe hearing impairment	353	14	658	15
Blindness or severe vision impairment	58	2	117	3
Physical disability	334	14	592	13
Learning disability	12	1	26	1
Mental health condition	120	5	185	4
Chronic pain lasting at least 3 months	395	16	638	14
Another long-term condition (including learning disability)	689	28	1,148	26
None of the above	1,192	49	2,280	51

Respondent Characteristics	Left at least one comment		All respondents	
	Number of respondents	Percentage	Number of Respondents	Percentage
Tumour Group				
Brain/Central Nervous System	21	1	39	1
Breast	659	25	1,187	25
Colorectal/Lower gastrointestinal	427	16	721	15
Gynaecological	213	8	359	7
Haematological	215	8	379	8
Head and Neck	148	6	264	5
Lung	163	6	292	6
Prostate	290	11	592	12
Sarcoma	20	1	34	1
Skin	70	3	129	3
Upper Gastrointestinal	118	4	189	4
Urological	173	6	308	6
Other / Tumour Group Unknown	146	5	342	7

Data Analysis

The free-text comments were analysed by a team of researchers using Thematic Analysis (Braun and Clarke, 2006). Details of the structured process used to analyse the data are provided in Appendix B.

Because of the nature and volume of the data, positive and negative codes were analysed separately, and are presented separately in the Results section.

We present the results of the free-text analysis using a range of approaches, in order to illustrate the large volume of data gathered as meaningfully as possible. First, an overview of the number and spread of comments for each section of the questionnaire is provided. This is followed by a description of the main themes arising from the analysis of the positive comments, and then a description of the themes arising from the negative comments. Finally, a breakdown of the subthemes arising from the positive and negative comments is provided for each comment box.

This report uses actual patient comments to illustrate the themes identified. Potentially revealing information has been removed from the comments, but they are otherwise presented verbatim.

Results

The breakdown of numbers of comments by top level category are given in Appendix C. Overall, there were more positive (2,528) than negative (1,969) comments. 671 participants made both positive and negative remarks within the same Comments Box. Participants also made 1,208 factual/neutral comments, and 585 miscellaneous comments. There were more positive than negative comments (a ratio of 1:0.78) for every comment box except Comment Boxes 1 (lead up to diagnosis) and 7 (experience of cancer care).

Proportionally, more negatively oriented comments appeared in Comment Box 1 than in any other text box, indicating that respondents were least happy with the lead up to diagnosis. Comments Box 3 had the highest proportion of positive to negative comments, indicating participants were proportionately more happy with the support they received (including from a clinical nurse specialist).

Due to the large volume of data, creating top level categories sorted responses into positive and negative comments, imposing a false dichotomy between positive and negative experiences. In reality, participants had variable experiences, not overwhelmingly negative. However, separating the positive and negative experiences allowed the analysis to focus on common issues when things either went right or wrong for patients.

Positive Comments

Overall, participants in the survey made more positive (2,528) than negative (1,969) comments about their cancer patient experience. Positive comments tended to be shorter and less descriptive and detailed than negative comments. The average number of words in positive comments was 24 words, compared to an average of 43 words in negative comments. Other cancer patient experience surveys have found a similar trend, with positive comments being less descriptive and of a much more general nature than negative comments (Wagland, Bracher, Esqueda, Schofield, Richardson, 2015). If people commented on a positive experience it was generally characterised by having good support, the system working quickly and efficiently, being given clear information, receiving good clinical care and having trust in the system (Figure 1).

Participants described a generally positive experience in terms of receiving good, great or excellent care, having no complaints, and being pleased and happy with their experience. This was a common positive, with 1,995 comments describing a generally good experience across all seven comment boxes.

“Could not have been better.”

Male, Age 66-75, Colorectal Cancer

“First class.”

Male, Age 76 and over, Lung Cancer

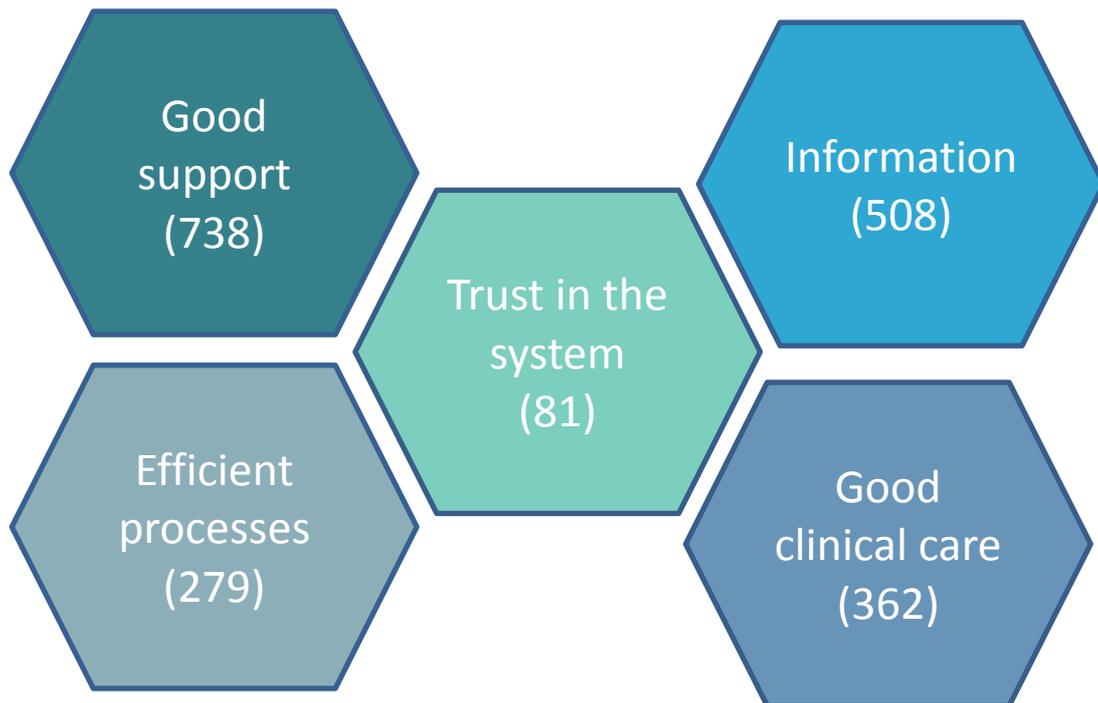


Figure 1: Positive aspects of care (number of comments)

Information

Comments suggest that respondents particularly valued being given clear information, and thorough explanations of their cancer and treatment, including treatment options. Patients appreciated staff being sensitive in the way they gave information, and taking the time to provide details about procedures. Positive comments were frequently made about being given detailed enough information to enable people to have clear expectations of their cancer experience. Overall, there were 508 positive comments about clear information.

“The cancer diagnosis and treatment plan was explained very clearly in detail on the first appointment. Subsequently this was very helpful in my expectations of all the treatments.”

Female, Age 51-65, Gynaecological Cancer

“All decisions were fully discussed and explained in a manner which was both sympathetic and sensitive, as well as in terms that I could understand.”

Male, Age 51-65, Upper Gastrointestinal Cancer

Efficient Processes

199 participants commented in a positive way about the speed of treatment. Comments related to the swift and efficient organisation of tests in the run up to diagnosis, not having to wait long on the day for outpatient or radiotherapy treatment, or being well informed about delays when in the waiting room.

A further 43 positive comments related to smooth and efficient processes around screening, and to being prompted by adverts or media articles to get tested for cancer. Many participants whose cancer had been identified through screening commented positively on the efficiency, information and support provided by the screening process, along with their relief that the cancer had been detected early before they had symptoms.

“From my doctor finding that I was anaemic and asking [hospital name removed] to look at my bowel it was all done within two weeks. Excellent by everyone.”

Male, Age 66-75, Colorectal Cancer

“My cancer diagnosis came about as a result of the bowel screening programme. I was not ill and had no symptoms and if not for the screening my outcome may well have been different.”

Male, Age 66-75, Colorectal Cancer

A small number of comments related to receiving treatment in a comfortable environment (21) and receiving local outpatient, chemotherapy or radiotherapy treatment, which participants felt made life considerably easier than having to travel for treatment (16).

Participants commented more fully on the specific importance of having good support during their cancer journey, having trust in the system, and receiving good clinical care.

Good Support

Good support was described as being looked after by staff who were caring, supportive, kind, approachable and informative, and who treated the patient as an individual (738 comments). Patients also appreciated staff being cheerful, friendly and professional. There were many positive comments specifically describing support from clinical nurse specialists and other nurses, particularly emphasising and valuing their role as a point of contact, information and reassurance.

Participants also described receiving support from a range of charities (e.g. Macmillan, Maggie's, Urological CANcers Aberdeen, CLAN Cancer Support, Citizens Advice Scotland etc) and commented on how valuable this was as an additional source of support, information and contact. However, many participants remarked that they had only heard about the support available from charities through word of mouth from other patients. Good support was described in comments about inpatient *and* outpatient care, but not in those made about the lead up to diagnosis or the way decisions were made about treatment.

“I have found that most doctors/nurses etc. (bar one!) have been so nice to me and understand how nervous and scared I can be. Having cancer is terrifying and at times a very lonely place, we need to be cared for in a kind and gentle way, we get very scared.”

Female, Age 36-50, Breast Cancer

“It was great having support from the nurse specialist. Before my surgery she took me through what may happen, colonoscopy etc. and what support would be available. Following discharge I contacted her at least twice for advice prior to carrying out some activities.”

Male, Age 51-65, Colorectal Cancer

“I did use Maggie's as someone recommended it, otherwise I wouldn't have known it was there. The help I got was from Maggie's and a short course delivered at Maggie's. That was very helpful. A consultant came to speak at it and I found having time to ask questions there was very helpful.”

Female, Age 51-65, Breast Cancer

Good Clinical Care

Good clinical care was portrayed (362 comments) as the treatment or operation going well and the patient receiving specific help with side effects or self-care. Many participants outlined the confidence they felt in their clinical care team, describing how they felt safe when they were treated by the same team both before and after surgery or treatment. A strong clinical team was epitomised as having a respected clinical team leader (oncologist or surgeon) who had met with the patient, and who, along with other team members, had provided clear explanations about treatment and procedures, with no conflicting messages. Good clinical care was reported in comment boxes relating to inpatient *and* outpatient care, chemotherapy and radiotherapy treatment, and overall experience of cancer care.

“I feel privileged, to be looked after by such professional medical teams of surgeons and nurses. Any worries I had before operation were easily cast aside by their answers. Having [condition removed] always adds additional care required after an anaesthetic, but again, I always receive it. My grateful thanks to you all.”

Female, Age 66-75, Breast Cancer

“I had very good pre-op and any post-op care while in for major surgery with specialist nursing for pain control. Clinical nursing specialist and excellent ward nursing care towards self care and enhanced recovery.”

Female, Age 66-75, Colorectal Cancer

Trust In the System

A number of respondents (81 comments) specifically expressed their trust in the system. Patients particularly conveyed trust in relation to clinical staff 'knowing best', and to all necessary experts being involved in their care. Trust arose as a particularly important issue around the way decisions were made about treatment, with participants valuing joint decision making – being spoken to with respect, and being involved in the decision making process.

“With [name removed] and [name removed] I felt very much that we were a team dealing with this together and they then discussed my case with the other specialists.”

Female, Age 51-65, Breast Cancer

“The most important consultation about possible treatment options at [hospital name removed] involved both the consultant urologist and a clinician from the [hospital name removed]. This was a most helpful arrangement which allowed me to understand the options very well.”

Male, Age 66-75, Prostate Cancer

Negative Comments

The 1,969 negative comments tended to be longer and more detailed than those describing positive aspects of experience.

Analysis of the main themes emerging from the data across all stages of the cancer journey (i.e. all comments boxes in the questionnaire) suggested two core issues at the heart of patients' negative experiences of care. These were (i) not feeling confident within the system and (ii) not feeling that individual needs were met. Within these core themes, a range of sub-themes characterised more negative experiences of care (Figure 2).

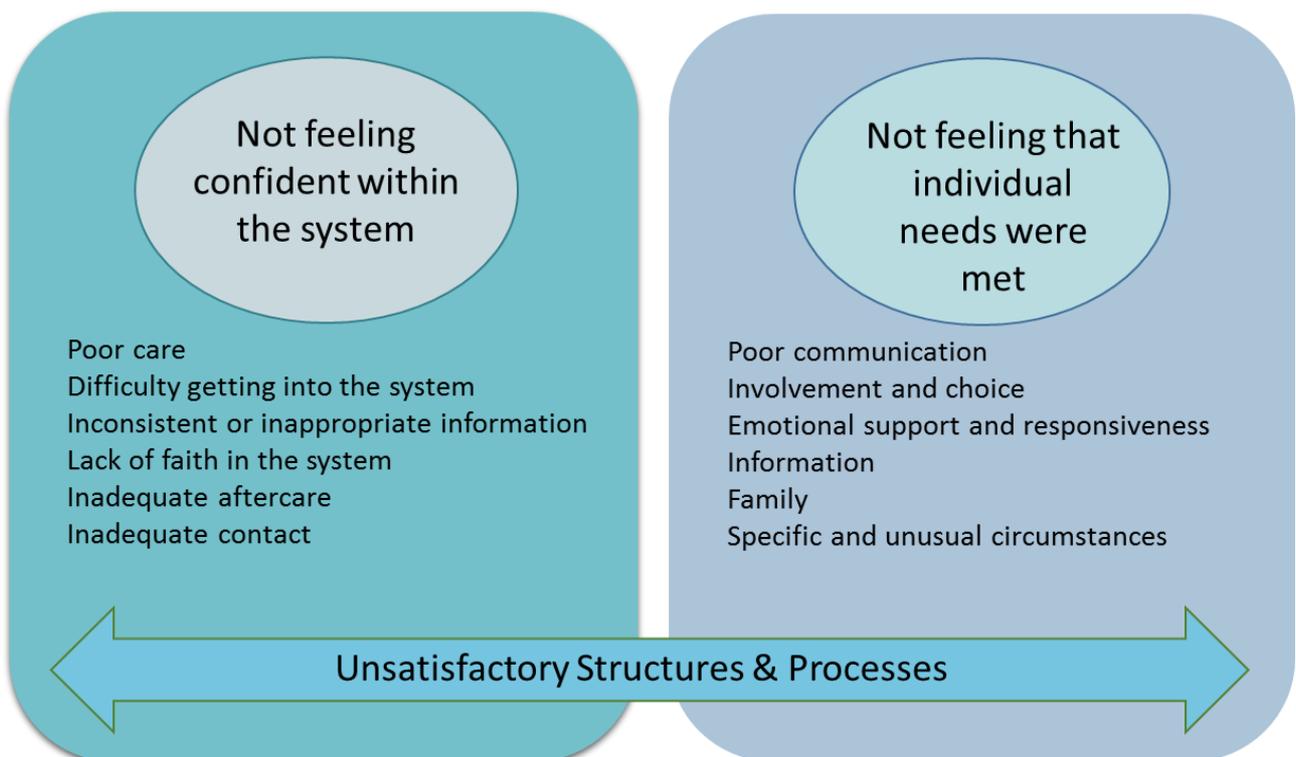


Figure 2: Negative Aspects of Care

Participants also discussed underlying issues with the system and the organisation of services which contributed to poorer experiences in both of these areas. These were characterised as problems with (i) structures – the way services and environments are set up; and (ii) processes – the organisation of care and treatment (Figure 2). An overview of the analysis is presented in Table 3; brief definition of the sub-themes is presented in Appendix D.

Table 3: Summary of the themes and sub themes

Themes	Sub Themes	Number of comments
Not feeling confident within the system	Poor care	372
	Inadequate aftercare	262
	Difficulty getting into the system	200
	Inconsistent or inappropriate information	158
	Lack of faith in the system	158
	Inadequate contact	50
	Total number of comments about Not feeling confident within the system	1,200
Not feeling that individual needs were met	Information	407
	Poor communication	345
	Emotional Support and Responsiveness	270
	Involvement and choice	97
	Specific and unusual circumstances	34
	Family	21
	Total number of comments about Not feeling that individual needs were met	1,174
Structures	Unsuitable or uncomfortable environment	145
	Staffing Levels	143
	Privacy	67
	Transport	49
	Total number of comments about Structures	404
Processes	Waits and delays	454
	Ineffective and unreliable processes (organisational systems)	289
	Fragmented care	276
	Total number of comments about Processes	1,019

Not feeling confident within the system

Thematic analysis revealed a number of negative experiences that appeared to relate to not feeling confident about their care or the way in which the system worked for them. These included receiving poor care, having difficulty getting into the system, receiving inconsistent or inappropriate information, having no faith in the system, receiving inadequate aftercare, and having inadequate contact with health professionals.

Poor care

Participants described a range of issues related to poor care including problems with treatment, being left alone and isolated, acquiring hospital infections, receiving inadequate pain relief and not feeling that side effects were managed adequately (372 comments). Many participants felt that hospital staff did not listen to, believe or understand their concerns – this was particularly the case for poor pain management and bowel problems. Respondents noted particular issues when receiving care from staff who had not been specifically trained in cancer care, commenting on differences in the quality of care they received on cancer wards or high dependency units compared to general wards. Patients reported feeling isolated on general wards, and appeared to feel that ward staff were unaware of and uncomfortable dealing with the needs of cancer patients.

Isolation was a particular issue for patients in single rooms, who could be left for hours without being visited by a nurse. Some participants felt that care at night and weekends was of poorer quality than during the day, with long delays due to staff shortages. Participants felt that the poor care they received resulted in clinical problems taking longer to be resolved and hospital stays being prolonged. In some cases poor care led to the patient having to be readmitted to hospital after discharge. Often patients described feeling ignored, isolated, alone and vulnerable, with staff rigidly following internal routines and regimens rather than responding to patients' needs.

“I was in severe pain following the operation, when I said so the nurses were talking among themselves that I couldn't be in that much pain, only to discover that I wasn't getting the correct strength of pain relief. I didn't find that the bedside manner of nurses are there any more. My daughter had to shower me. I had a bed sore and hair had to be cut due to it being matted.”

Female, Age 36-50, Colorectal Cancer

“During the day the ward was well staffed with qualified cancer nurses, although they were under severe pressure at times. At night, staffing was inadequate to cope with the demands of very ill patients and at times treatment and medication were badly delayed due to emergencies.”

Female, Age 66-75, Haematological Cancer

“Being admitted was the worst experience I could possibly have had. To say the staff were inexperienced in caring for cancer patients was an understatement. I couldn't talk because my mouth was so sore and swollen, my partner was telling them what was wrong and the two nurses on duty stood at the end of the bed and discussed between themselves as though we weren't there on how they had never heard of my condition before.

None of the staff knew how to take blood or administer drugs through a Hickman Line so they had to get one of the nurses down from the ward to show them. I was eventually put into a room by myself where a nurse from another department was helping out... They tried to send me for a CT scan, I refused, but it turned out that I wasn't the patient they were looking for.

All in all I spent seven hours without any real treatment for my condition. Treatment only started once I had been transferred up to the ward. Staff need much, much more training so they can competently deal and treat cancer patients.”

Female, Age 36-50, Haematological Cancer

Difficulty getting into the system

Another source of concern for participants was the difficulty they experienced in receiving a cancer diagnosis (200 comments). Many respondents described having multiple visits to their GP practice, sometimes over months and years, before undergoing the diagnostic tests for cancer. During this time they were either told that nothing was wrong, or they were treated for a range of other wrongly diagnosed ailments, while continuing to struggle with their cancer symptoms. These participants felt their GPs had: insufficient awareness and knowledge of cancer and the common symptoms; paid insufficient attention to the patient's concerns; and were sometimes unwilling to refer the patient for diagnostic testing. Some patients described bypassing their GP by going to A&E or using private healthcare in order to be diagnosed, others described collapsing and being admitted to hospital as an emergency due to lack of earlier diagnosis and appropriate treatment.

“My GPs weren't very good. I had to eventually press them for an urgent referral. I knew there was something wrong. I had a tumour in my larynx, whilst my GP kept on treating me for asthma when previously I had been a fit individual so it was obvious I had/have a good set of lungs on me, not asthma. It took over 6 months to get to see a consultant. There was even another symptom - tingling fingers that could have pointed the GP in the right direction. If blood tests had been carried out they may have showed up reduced blood calcium levels, a symptom of which can be tingling fingers, which I had told the GP about at my first visit but was misdiagnosed.”

Male, Age 36-50, Lung Cancer

Inconsistent or inappropriate information

Being given wrong or conflicting information was a cause of confusion, worry and anxiety to participants (158 comments). This was a particular problem during diagnosis if the patient was told their tumour was benign, only to discover after further tests that it was cancerous, or when the patient's expectations were set that they would receive 'simple' treatment, to then find out later that their treatment would be much more complex and invasive.

“I feel that the way I received the diagnosis information was not thorough enough or consistent. I do understand that a full diagnosis cannot be done until all the screening tests are completed, but that does not mean that I should receive contradictory information. In fact, I was so confused that I had to chase up a full explanation from the consultant, who was not available the first time my results were in. The breast nurse did this, but wasn't very supportive or informative, i.e. said the diagnosis confirmed that the cancer was invasive when I was previously told that it wasn't. She was on the computer looking for the details of the next patient when I was still there trying to find some answers of why information was omitted from me. This created a lot of anxiety as I was trying to research information on the web to try to understand.”

Female, Age 36-50, Breast Cancer

Participants also described being given unclear and conflicting information by different health professionals and specialists involved in their treatment. This lack of consistent information made it difficult for some patients to feel confident in the decisions that were made about their treatment.

“Too many doctors were telling me different things, I got a bit confused by all the different stories the doctors were telling me. I didn't know who to listen to.”

Female, Age 66-75, Upper Gastrointestinal Cancer

Lack of faith in the system

Several participants described having lost faith in the system (158 comments), not trusting that a deterioration in their health would be picked up. Participants described instances when tests were not carried out at all, not carried out at the correct time, tests did not pick up the cancer, results were wrongly interpreted, or they were not given timely or clear feedback on the results of tests. As a result, participants required a lot more reassurance that their cancer treatment had been successful and that their health was being monitored effectively.

“It's well over a year since I had my tumour removed but the bone has not been scanned again. I am also concerned about this cancer has spread throughout my body as it was there for several years before it was removed.”

Male, Age 51-65, Head and Neck Cancer

Inadequate support after treatment

In addition to concerns about monitoring, many participants made comments about inadequate support after treatment (262 comments). Participants described confusion over who was responsible for care after treatment, with patients not receiving clear communication, or having a clear understanding of (i) who they should contact for ongoing support, and (ii) what should happen next in their cancer care. This was described by participants as being frightening, and led to patients feeling anxious and isolated. Patients were often left with debilitating side effects as a result of treatment, and many struggled to manage physically and emotionally when back at home. Many participants received no help or advice about self-care or how to self-manage side effects, and were discharged from hospital with no care plan, inadequate support at home, and no access to specialist services for additional support.

Several respondents commented in particular about the lack of support they received from their GP practice after treatment, describing an absence of contact from their GP practice, difficulties with attending the practice after major surgery, and their GP having little awareness of cancer treatment, side effects, or palliative care.

“Very disappointed felt like the cancer I had wasn't important enough. I have had nothing but struggles since having cancer and feel completely disappointed I wasn't giving a MacMillan support nurse. Nothing! Dealt with most of it on my own and left wondering had my cancer been cleared or not since no one informed me.”

Female, Age 16-25, Head and Neck Cancer

“Post-op I was discharged with no advice on how to best mobilise and no walking aids, no physiotherapy or advice on footwear. I waited weeks to see orthopaedic consultant to have an insole made. In those weeks I still needed to walk about. Very painful and difficult.”

Female, Age 66-75, Skin Cancer

“I was sent home from Hospital with no care plan - I live on my own and had a difficult time to do things, nurse had told me everything was as planned and people would come to my home to help for a few weeks, but no one came. I was left on my own.”

Female, Age 51-65, Lung Cancer

Inadequate contact

A small number of participants commented (50 comments) that they did not feel they had received adequate contact with cancer specialists. In some cases, participants reported either seeing a specialist clinical nurse, or a more junior doctor, however, this was not felt to be as reassuring as seeing an oncologist.

“I am checked up at dermatology and plastic surgery clinics. I rarely see a cancer specialist apart from the specialist clinical nurse. If this is a common experience arrangements should be made for the patient to be seen by an oncologist from time to time.”

Female, Age 51-65, Skin Cancer

Not feeling that individual needs were met

Alongside not feeling confident within the system, the other major theme which negatively affected patients' experience of cancer care was not feeling that individual needs were met or respected. A range of issues fell within this theme, and contributed to patients feeling that their individual needs were not met. These included poor communication, lack of involvement and choice, poor emotional support and responsiveness, lack of information, lack of support for families, and difficulties with specific and unusual circumstances.

Poor communication

Many participants described experiencing communication problems at some point during their treatment (345 comments). These were particularly notable in the lead up to diagnosis, but were reported at all points of the cancer journey. Participants described feeling that staff did not listen to them or treat them with respect. Although they acknowledged that most staff were pleasant to them, many participants described isolated interactions where communication was rude, insensitive, impersonal, blunt, dismissive, condescending, cold and uncaring. At the time of diagnosis, respondents did not appreciate dramatic and fatalistic, or unclear communication, nor did they appreciate receiving an overload of information. A number of participants were never actually told in so many words that they had cancer, and others were told in a vague way using euphemisms – both approaches left patients feeling confused about their health.

“To be honest, I don't completely remember being told I had cancer, perhaps it would have been better if they made it clearer rather than using medical terminology.”

Male, Age 36-50, Urological Cancer

“On admission for my sentinel node biopsy I was asked would I prefer to die at home, in hospital or in a hospice! I found this quite shocking and upsetting to be asked this when I was only just diagnosed, very frightened, and not terminal!”

Female, Age 36-50, Breast Cancer

“I was made to wait 2 hours. The specialist, who I believe is [detail removed], was more interested in their paperwork than explaining my problem and was very insensitive.”

Male, Age 66-75, Prostate Cancer

Lack of involvement and choice

This was another aspect of care which appeared to contribute to participants feeling their individual needs were not met (97 comments). Some felt they were not involved in making decisions about their treatment, or felt pushed into making a decision. A small number of patients with breast cancer wondered later whether they should have had preventive mastectomies, but were not offered this as an option at the time. Some participants felt they had been given no choice as to their treatment, that their options weren't made clear to them, or that the options they were interested in were not available to them. Other participants commented that

while they had been given options to choose from, they would have valued a recommendation or steer from the experts.

“It is helpful to hear about treatment options, but sometimes it would be good for an expert to tell you what to do. A difficult balance I know, but my GP stepped in when I became paralysed by indecision.”

Female, Age 36-50, Skin Cancer

“We only saw the consultant once and that was when we asked to speak to someone about transport and staying at [location removed]. My wife ventured to ask [gender removed] about alternatives to radiotherapy but was abruptly told that this was the treatment decided for me. Very upsetting! Never saw them again!”

Male, Age 66-75, Prostate Cancer

Poor emotional support and responsiveness

Many participants felt that they did not get the level of emotional support which they needed (270 comments). Types of support sought by participants included sympathy, reassurance, counselling, contact, help with emotions, detailed explanations, someone to talk to, company, practical advice, and being warned or prepared for next steps. Comments suggested that patients felt unsupported if they did not have contact during and after treatment with the people they perceived as being providers of support, for example if they were not assigned a clinical nurse specialist, or had only briefly or never met a specialist nurse; or were not able to access a Macmillan nurse. Continuity of support was an issue for some participants if their assigned nurse was part-time, went on holiday or changed role and they were not made aware of a replacement contact. Lack of support during and after treatment left patients feeling alienated, isolated and alone.

Several participants commented that they had not brought family or friends with them to an appointment, including at the time of diagnosis, because they had not been expecting to receive a diagnosis. This was usually because they were attending for a biopsy and didn't expect to receive the results so quickly, or because they had previously been led to believe that their tumour was probably benign. Participants felt that some prior warning that they might receive a cancer diagnosis would have helped them to prepare for the news.

“When I was having chemo I did get a little depressed and felt very isolated. I did go to my GP and asked for help just to talk to someone, they said there was nothing. So I just had to get on with it. It was a lonely time for me, but I just got on with it. There was the Macmillan at [hospital name removed] but when you are so ill, it was hard for me to go there.”

Female, Age 51-65, Colorectal Cancer

“I met my clinical nurse specialist for the first time at a three monthly follow-up clinic, eighteen months after my surgery. It would have helped me a great deal to have met her at the time.”

Female, Age 51-65, Tumour group not known

“I had a biopsy taken and I was told twice by the nurse/doctor performing this that "it was certainly nothing to worry about". I had no idea I was going to be told the news I did and if I had an inkling, I would have taken my husband or a family member with me.”

Female, Age 36-50, Head and Neck Cancer

Lack of information

Many participants did not receive the amount or type of information they required to meet their individual needs (407 comments). For a small number of participants, this meant being given too much information at once, leading to participants feeling rushed, struggling to process the information, and in some cases making patients feel anxious and frightened. However, more frequently, participants felt they did not receive enough information, in particular information about side effects of treatment. Many participants felt that prior to making decisions about treatment, they would have liked to receive a much more detailed explanation of treatment, what to expect, and likely or potential side effects and consequences of treatment. After treatment, participants would have appreciated more detailed advice and information on how to recognise and manage side effects, and how to self-care after surgery, including receiving realistic information about recovery times.

The other area where participants felt they received inadequate information was around being signposted to additional services. Many participants had individual needs for welfare advice, emotional support, physiotherapy, and nutritional advice, which could have been met by other NHS services or charities, yet the participants were not told about these services.

“Macmillan support, Maggie Centre, financial advice etc. Nothing was ever mentioned or offered at any time, by anyone.”

Female, Age 66-75, Colorectal Cancer

“Information about side effects too vague e.g. you might get this, you might get that, not how bad it could be or what to do about it. The nurse who gave me the drugs to take home went through everything very quickly with no written information. The information on the [word unreadable] were inadequate and in one case completely wrong and led to dreadful side effects.”

Female, Age 51-65, Haematological Cancer

Lack of support for families

A small number of participants commented on the lack of consideration for their family while they were being treated for cancer (21 comments). Some participants described the difficulties their family members had encountered when trying to find out information from specialists about their care. Another source of concern was the difficulty patients experienced in having family members visit them in hospital or clinics. This was particularly problematic when patients were forced to wait alone for procedures, when they would have felt much more relaxed waiting with a family member.

“My chemotherapy treatment began as an outpatient. I took ill and was admitted to ward [number removed] in [hospital name removed]. I felt that I was not treated there as a person there but a thing on a " to-do list". Although I spent many hours there with nothing happening my wife was excluded after the first 10 minutes. She was even handed a piece of paper saying that this is the ward policy. This was the only time in hospital where I feel the staff had forgotten that patients are human beings. At that point it looked like death was not very far away and emotional support from my wife was very important for me.”

Male, Age 51-65, Colorectal Cancer

Specific individual needs

A small number of participants had specific individual circumstances which affected their treatment or care needs (34 comments). Participants felt that these specific circumstances were not sufficiently taken into account for aspects of their diagnosis or care. Particular problems arose for patients (i) with disabilities, or comorbidities; (ii) with a family history of cancer; (iii) whose location meant they were unable to access services; (iv) whose fertility was affected by their cancer treatment. Participants felt that the support provided around their diagnosis or treatment was insufficiently sensitive to their specific needs.

“The cancer treatment affected my fertility but no options were discussed prior to treatment starting and I didn't know there were options available to me until it was too late. This was a really difficult thing to find out as I may have chosen to freeze eggs or embryos and now I can't.”

Female, Age 36-50, Breast Cancer

“The service was very slow to give the diagnosis and the attitude of "wait and see" was unacceptable given that the family history indicated a very high risk of that particular type of cancer. A complaint had to be made to bring the appointment forward and on the whole the appointments system was in my view a shambles. Once the diagnosis was made the process was satisfactory and the support outstanding.”

Male, Age 51-65, Prostate Cancer

Structures

Participants described a number of problems with the way the healthcare system or environment of care was structured, and these negatively impacted on their experience as a cancer patient. These structural problems included aspects of the care environment, difficulties with transport, inadequate staffing levels and lack of privacy.

Care environment

Comments about the care environment (145 comments) were most often related to staying overnight in hospital, and included: concerns about the food not being suitable for specific cancer patient needs or not meeting clinical recommendations following certain types of treatment; hygiene issues, especially in relation to shared ward toilets; high noise levels on wards, particularly ward staff chatting loudly at night when patients were trying to sleep; and uncomfortable beds and chairs. Participants also commented negatively about problems with bed or chair availability and how these impacted on their experience, both as inpatients and during outpatient chemotherapy treatment. Bed availability was a particular problem at admission, and again at discharge, with some patients being left in pain for hours without a bed. Several participants commented on insufficient or broken facilities impacting on their comfort or their care, for example broken buzzers, lights, televisions, or lack of blankets, dressings, colostomy bags.

“I had operation in [hospital name removed], my week in unit [name removed] was very good, nursing staff to patient ratio excellent. But then in general ward not enough staff to deal with amount of patients who needed some form of assistance and at weekends ran out of dressings/towels and bedding because stores closed. Staff were excellent but understaffed and overworked.”

Male, Age 51-65, Upper Gastrointestinal Cancer

“Noisy ward at night. Nursing talking/giggling. No concern for patients trying to sleep.”

Male, Age 51-65, Colorectal Cancer

Transport

Problems with transport contributed to a very negative cancer experience for the relatively small number of patients who commented on this (49 comments). Difficulties included: problems with parking; ineligibility for, or lack of availability of patient transport, meaning some patients had to travel home after chemotherapy or surgery on public transport; and the high cost of transport. Cancer treatment and diagnostic tests being carried out in multiple locations meant that patients often had several long journeys in one week, even though they were feeling poorly; this was particularly problematic if appointments were made for first thing in the morning. Although only affecting a very small number of patients, cancer care for people from the Islands was notably difficult, both due to the lack of support for cancer patients on the Islands, and the difficulties of travelling by ferry when there are no facilities for patients on the boat.

“Found it very tiring travelling [number removed] days per week for 4 weeks to [hospital name removed] for radiotherapy by public transport. I enquired about patient transport, but they could not accommodate my appointment times.”

Female, Age 66-75, Breast Cancer

Inadequate staffing levels

Staffing levels were mentioned at all points of the cancer journey (143 comments), but particularly in relation to overnight stays in hospital. Participants felt that wards and clinics were understaffed, and the staff who were working were very busy and had too many patients to deal with. Patients did not want to bother staff because they were so busy, and this meant that patients were unwilling to ask for help or support. Outpatient appointments were rushed due to the volume of patients, resulting in patients not having an opportunity to fully discuss their cancer, not having time to ask questions, and not feeling listened to.

“I'm just out of [hospital name removed] and there were definitely not enough nurses. I would ask for something, the answer would be "back in a minute", but then they would disappear off the planet.”

Male, Age 66-75, Lung Cancer

“Felt nurses were busy and I felt I did not and was not able to be spoken to as a person. Breast care nurse allocated I saw about four times. I felt if I managed to get her she would say "need to go" all the time. So I gave up and I still struggling with this very badly.”

Female, Age 51-65, Breast Cancer

Lack of privacy

Lack of privacy was a serious issue for a number of respondents (67 comments), particularly at the time of diagnosis and when staying overnight in hospital. At the time of diagnosis, patients felt uncomfortable receiving a cancer diagnosis when there were lots of people in the room, or receiving their diagnosis over the telephone when they were in a public place. When staying overnight in hospital, patients felt intensely embarrassed, vulnerable and exposed to have personal details about their treatment and cancer prognosis discussed on the ward with only a curtain separating them from other patients. Several colorectal cancer patients also mentioned how undignified they felt during procedures, and while learning how to manage drains and stoma on a ward.

“Ward with several patients sharing meant there was no privacy to discuss my condition or treatment. Everyone could hear everything. I had an unplanned stoma and had to learn to manage it on a shared ward with one toilet. I didn't want anyone to know I had a stoma, but it felt like everyone did. I found the lack of privacy very distressing. There wasn't even anywhere I could cry in private.”

Female, Age 51-65, Colorectal Cancer

“My abiding memory about being told what was wrong with me was lying in a ward with the curtains drawn around the bed. I was fairly bluntly told that there was nothing that could be done to help me. It was pretty shocking and when the curtains were opened I knew that everyone else on the ward had heard too. My [family member removed] was with me but I still felt very exposed, vulnerable and helpless.”

Female, Age 66-75, Tumour group not known

Processes

Participants also described numerous problems with the organisation of treatment and care. Processes which negatively affected their experience included ineffective and unreliable administrative systems, waits and delays and fragmented care.

Administrative systems

Participants described struggling with a number of the processes used by the NHS to manage patients including administration of letters and appointments, administration of patient notes, and call handling (289 comments). Problems with the administration of letters and appointments included: delays for letters to be sent to GPs and patients; no appointments being sent out for scans, surgery, the start of radiotherapy and chemotherapy, and follow-up clinics; and appointments being cancelled or postponed without adequate communication. Participants described the administration system as being 'not fit for purpose' and chaotic, and viewed this as putting their healthcare at risk. A frequent concern of respondents was that they had been told by clinical staff that they should have regular follow-ups after cancer treatment, however, the administration system either reduced the frequency of appointments, or regularly sent the appointments out months late, so that the patient never received the level of follow-up care apparently recommended by clinicians.

Many respondents commented on the inefficient administration of tests and scan appointments in relation to follow-up clinic appointments with specialists – with tests frequently occurring after follow-up appointments, meaning that test results weren't discussed until the next appointment which was often months later. Administration of patient notes and test results was an issue for several participants, who reported notes and results going missing or being mislaid. Problems with call handling included difficulty with getting hold of named contacts, calls not being returned, delays in response times to calls, and patients not being given correct phone numbers to call for assistance.

“Follow up appointments not adhering to the six monthly timescale I was told about. I also feel that as a patient I should be informed of results of tests undertaken as soon as possible. Recently I had an ultra scan and x-ray carried out and my next appointment with my consultant is not until four months later. It would be re-assuring to know that everything is fine.”

Male, Age 51-65, Urological Cancer

“Firstly I was given an incorrect number. When I did eventually make contact my nurse was on leave and the person who answered my call was unable to advise me. A follow-up call went unanswered for so long that the reason had become irrelevant. I did not call again.”

Male, Age 51-65, Prostate Cancer

Waits and delays

The greatest number of negative comments in this theme concerned waits and delays (454 comments). These were frequently made alongside comments about

ineffective administration. Participants experienced waits and delays waiting for appointments, waiting for surgery, and sitting waiting on the day for outpatient and chemotherapy appointments. Participants described experiencing a high level of stress and anxiety due to waits and delays, and in some cases reported that their cancer had progressed or spread during the time they were waiting to be treated.

Three circumstances were frequently described as being associated with difficult periods of waiting (i) being on the waiting list for surgery for much longer if the patient had chosen breast reconstruction instead of mastectomy only; (ii) waiting for hours in the hospital for an operation with no food or water after being asked to come in for a morning appointment; (iii) waiting for hours to receive chemotherapy because the drugs had not been sent down from the pharmacy.

“Felt pressurised into just having mastectomy. They said everything I wanted involved two surgeons and was a very hard operation. Told mastectomy could be done within 6 days, yet had to wait 9 weeks approx. for my reconstruction and mastectomy op. Too long.”

Female, Age 51-65, Breast Cancer

“Had to be at hospital on morning of operation for 7:30. However, was left sitting in the waiting room till after lunch before being given a bed, then left till 5pm until called for surgery. As never had surgery before, found just being left all day very stressful.”

Female, Age 66-75, Breast Cancer

Fragmented care

Many participants described receiving treatment and care which seemed fragmented because numerous people were involved from different departments and hospitals (276 comments). Participants expressed the negative effect this fragmentation had on their anxiety levels and confidence in their treatment. Particular issues outlined by patients included that: different teams didn't have access to notes and there was poor communication between departments; different people involved didn't know what tests or procedures the patient had already received, and made conflicting decisions about treatment plans; the patient had no point of contact regarding their treatment and felt that no health professional had ownership or control of their case as a whole; overall, patients described a lack of continuity of care, feeling passed around and receiving a varying quality of treatment which was not joined up.

“Other than my consultant [name removed], the other doctors at both the [hospital names removed] do not seem to know any details at all about me or my treatment, even asking me what medication and dosage I am on.”

Male, Age 51-65, Head and Neck Cancer

“I did not like that there was no apparent overall control. I was sent to different specialists who only spoke about their own expertise.”

Male, Age 51-65, Urological Cancer

Analysis of Individual Comment Boxes

Each of the seven free-text comment boxes were analysed at the sub-theme level to identify the major issues for patients at that point in their cancer experience. All subthemes which represent at least 5% of the comments for that comment box are included in the following charts. All subthemes which represent less than 5% of the comments for that comment box are amalgamated into the 'Other' section for each chart. Although there is no double-counting of respondents' comments within any sub-theme, an individual respondent could contribute to more than one sub-theme in any given comment box if their free-text comment covered several issues.

The lead up to diagnosis and finding out what was wrong with you (Comment Box 1)

Positive

Analysis of the positive subthemes for Comment Box 1 indicate that respondents valued being given clear information, having a generally positive experience, and speed of treatment (Figure 3). 567 positive comments were coded into subthemes in Comment Box 1.

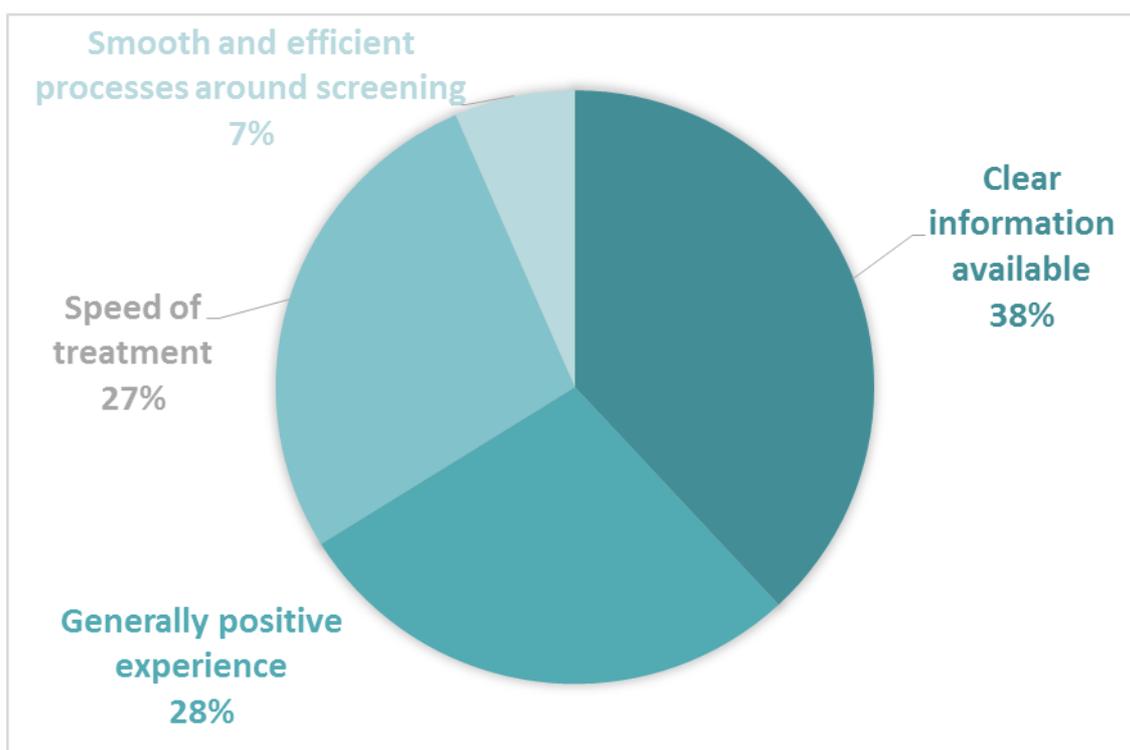


Figure 3 Positive subthemes for Comment Box 1 – Lead up to diagnosis

Negative

Breakdown of the negative subthemes for Comment Box 1 indicates that patients had particular issues with waits and delays, difficulty getting into the system, and poor communication in the lead up to diagnosis (Figure 4). 987 negative comments were coded into subthemes in Comment Box 1.

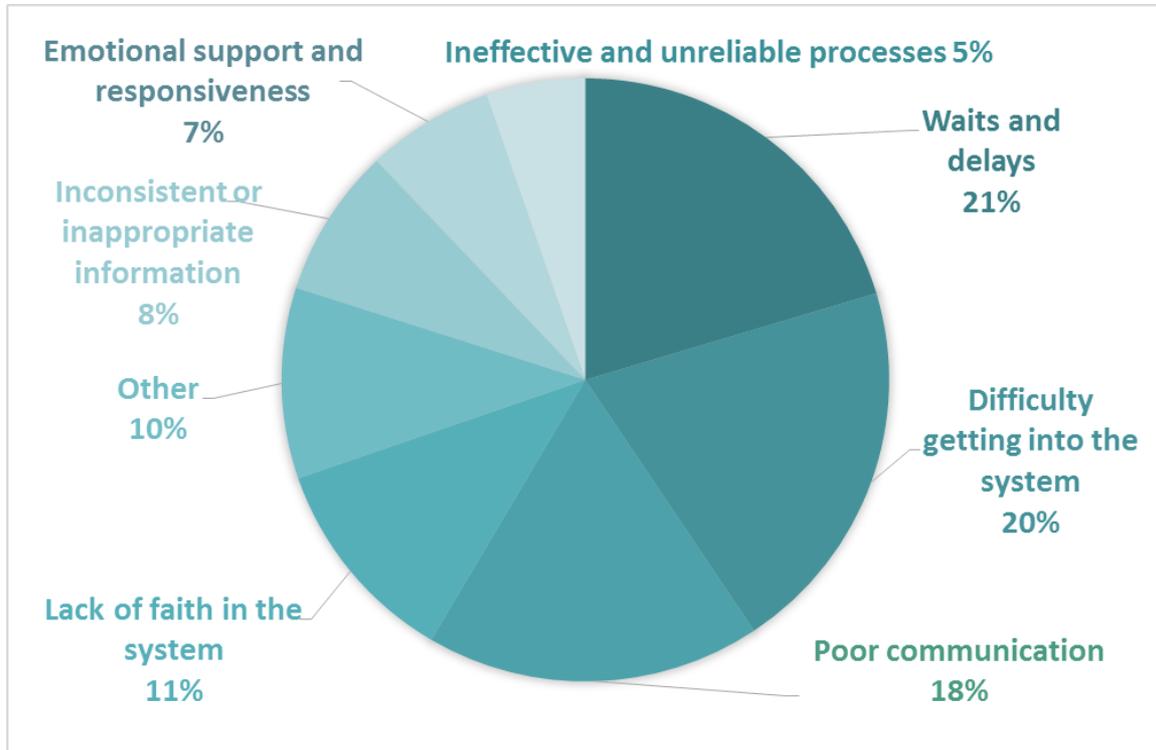


Figure 4 Negative subthemes for Comment Box 1 - Lead up to diagnosis

Decisions about treatment (Comment Box 2)

Positive

The most common positive subtheme for Comment Box 2 was having clear information available (Figure 5). Participants liked receiving explanations about treatment and procedures, having their options clearly explained and having their expectations set about outcomes, at the time of decision making about treatment. 423 positive comments were coded into subthemes in Comment Box 2.

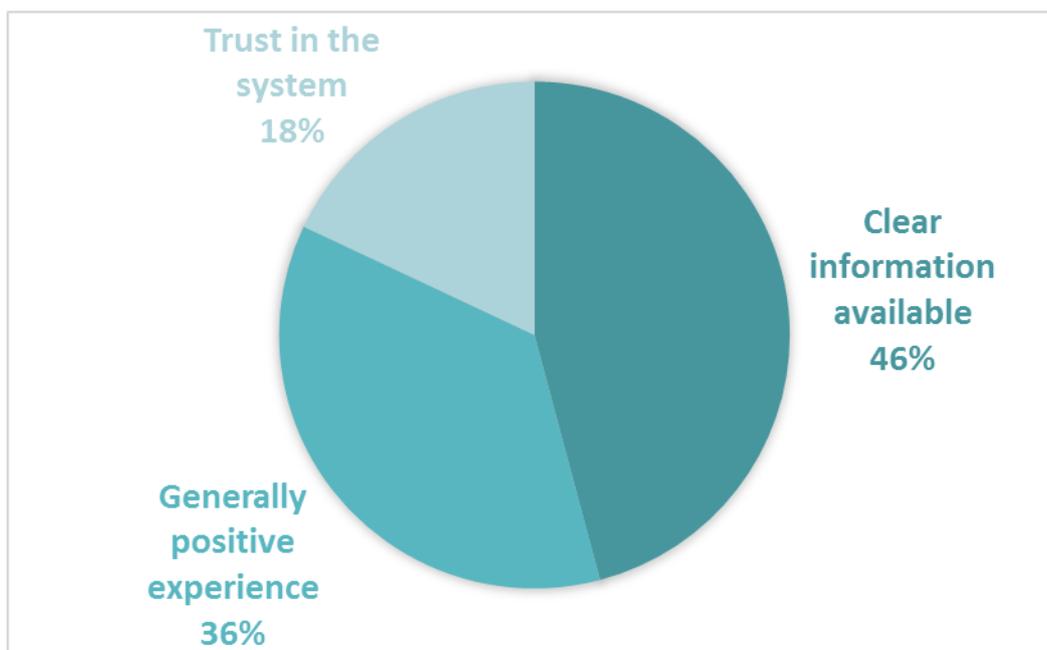


Figure 5 Positive subthemes for Comment Box 2 – The way decisions were made about treatment

Negative

Breakdown of the negative subthemes for Comment Box 2 indicates that patients' negative experiences of the way decisions were made about treatment centred around unmet information needs and lack of involvement and choice in decision making (Figure 6). Participants described unmet information needs at the time of decision making in terms of being given inadequate explanations of treatment, outcomes or side effects. Several participants commented that a clearer knowledge of likely side effects might have changed their treatment decisions; others felt that being prepared for side effects would have helped with self-management after treatment, and reduced needless worry about whether symptoms were side-effects or new cancer symptoms. 353 negative comments were coded into subthemes in Comment Box 2.

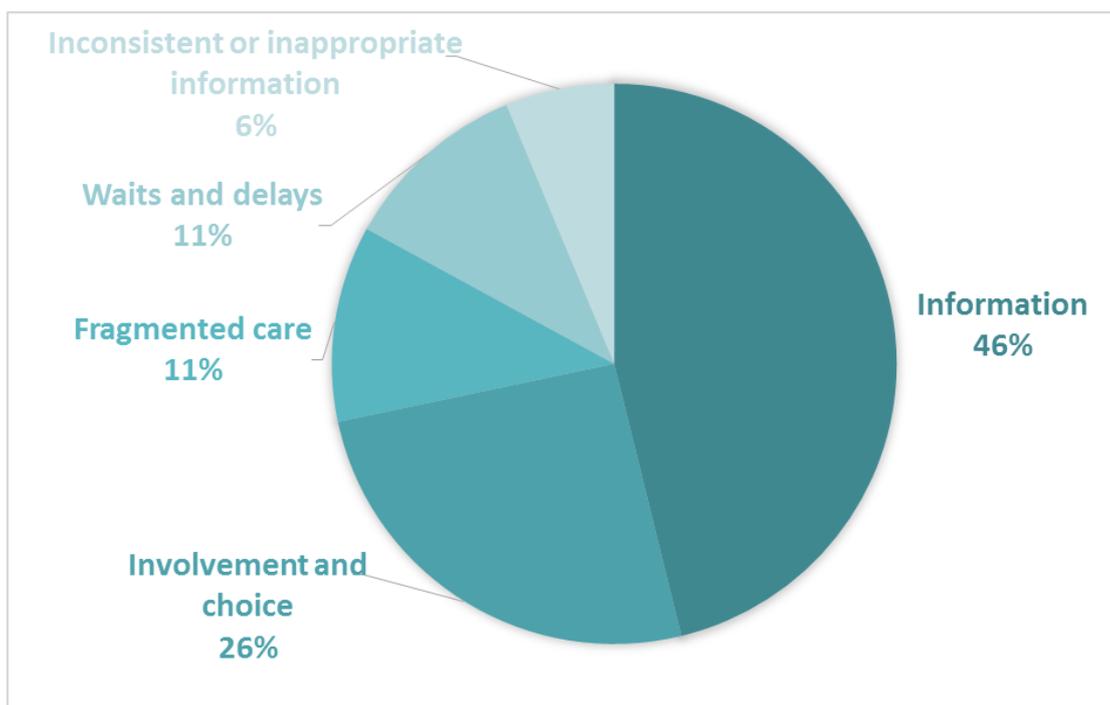


Figure 6 Negative subthemes for Comment Box 2 - The way decisions were made about treatment

Support (Comment Box 3)

Positive

Over half the positive comments in Comment Box 3 related to receiving good support (Figure 7). Participants were often positive about the support they received from a clinical nurse specialist or other cancer specific nurse, describing staff as supportive and approachable, and available to offer support. Participants also described receiving support from a range of charities. 621 positive comments were coded into subthemes in Comment Box 3.

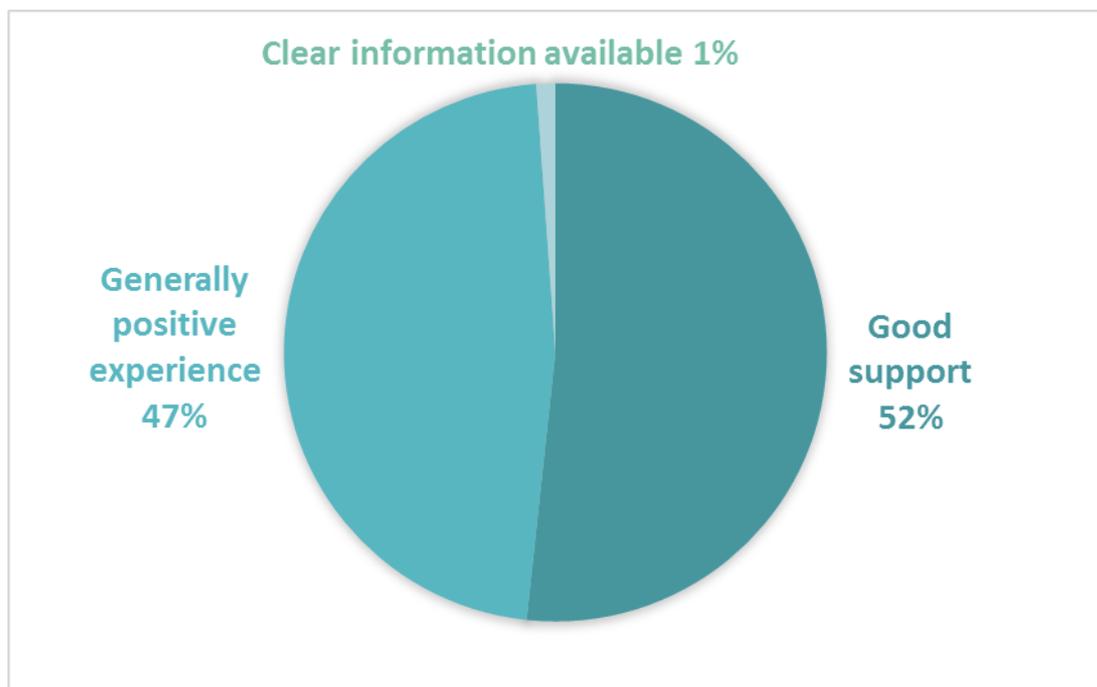


Figure 7 Positive subthemes for Comment Box 3 – The support you received

Negative

Breakdown of the negative subthemes in Comment Box 3 shows that common issues related to negative perceptions of support included lack of emotional support and responsiveness and lack of information (Figure 8). The concept of 'support' meant different things to different participants, with frequent interpretations of the word support being sympathy, contact, counselling, detailed information and signposting to services. Respondents to this comment box described that lack of emotional support left them feeling alienated and alone. Many described having had expectations that they would receive emotional support and care from their clinical nurse specialist (CNS), but feeling that in reality their CNS was busy and did not have time to maintain contact with them. This comment box came directly after explicit questions about the CNS, which may explain why CNSs were specifically mentioned in the comments. Many patients also commented on receiving fragmented care, and on ineffective and unreliable processes. 446 negative comments were coded into subthemes in Comment Box 3.

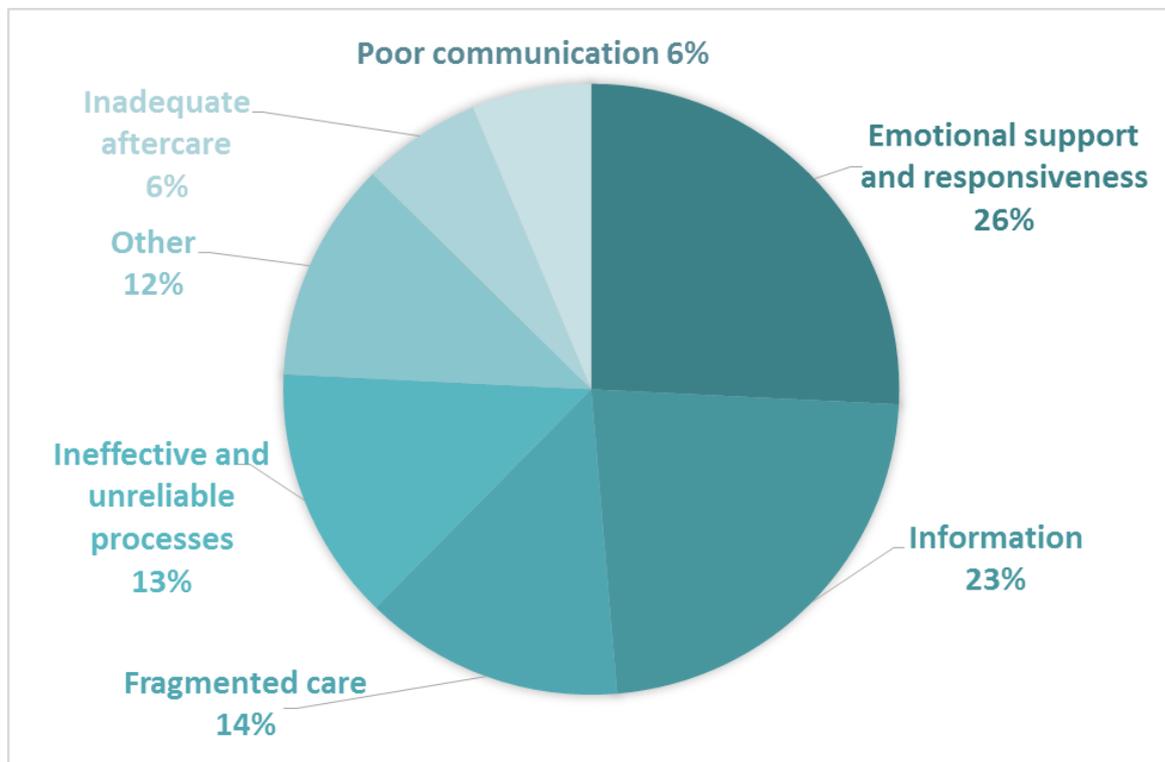


Figure 8 Negative subthemes for Comment Box 3 - The support you received

Operation or overnight stay in hospital (Comment Box 4)

Positive

The majority of positive comments about having an operation or overnight stay in hospital related to having a generally good experience (Figure 9). Participants also commented positively about receiving good support and good clinical care. 705 positive comments were coded into subthemes in Comment Box 4.

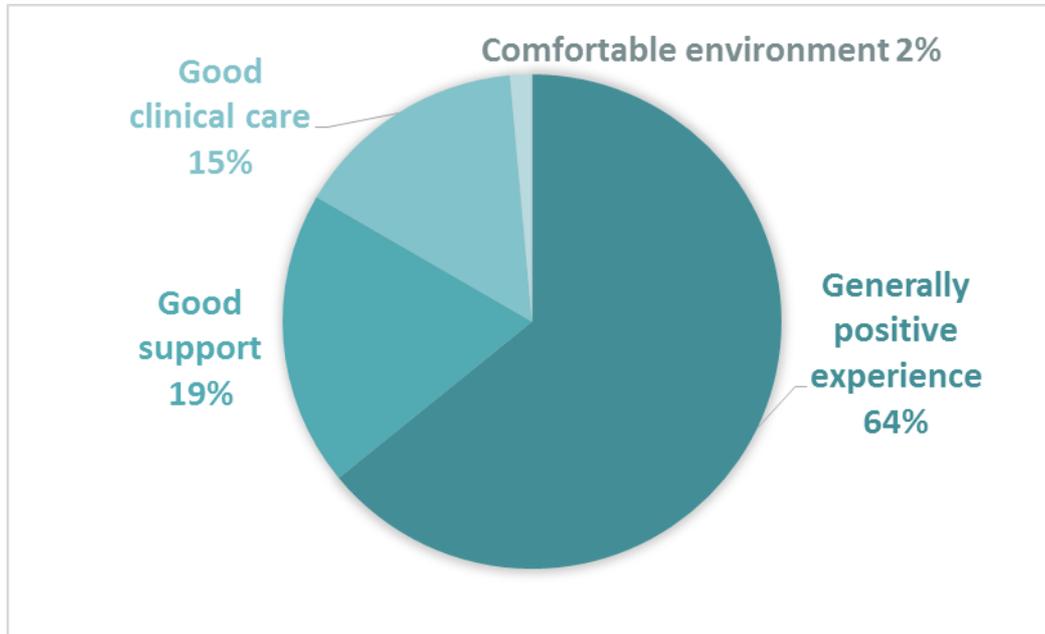


Figure 9 Positive subthemes for Comment Box 4 – The care you received when you had an operation or stayed overnight in hospital

Negative

Several issues emerged in response to Comment Box 4 (Figure 10). The most frequent negative comment related to receiving poor care – patients feeling that their individual needs were not being addressed, particularly in relation to side effects, pain and bowel issues; feeling that general ward staff did not understand the specific needs of cancer patients; and feeling ignored and isolated when staying overnight in hospital. Other common issues related to the environment being uncomfortable or unsuitable, and inadequate aftercare, for example being discharged too quickly, or not receiving help with how to self-manage. 662 negative comments were coded into subthemes in Comment Box 4.

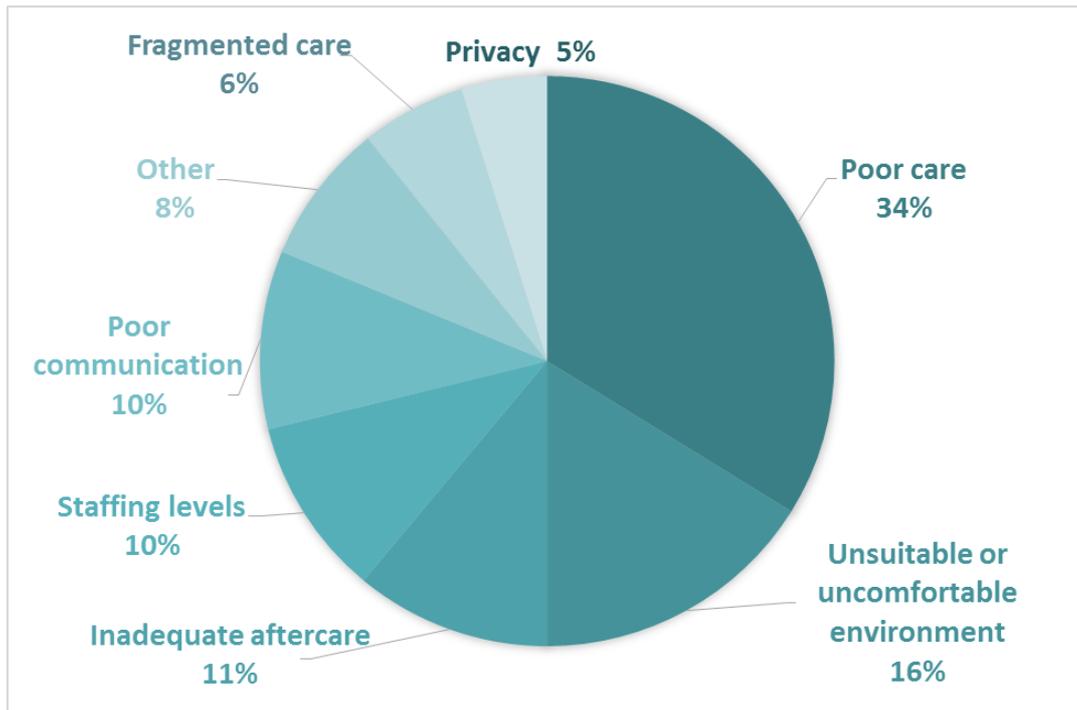


Figure 10 Negative subthemes for Comment Box 4 - The care you received when you had an operation or stayed overnight in hospital

Day patient/outpatient care (Comment Box 5)

Positive

Breakdown of the subthemes for Comment Box 5 indicated that most positive comments described having a generally good experience (Figure 11). Participants also commented positively about receiving good clinical care and good support. 475 positive comments were coded into sub-themes in Comment Box 5.

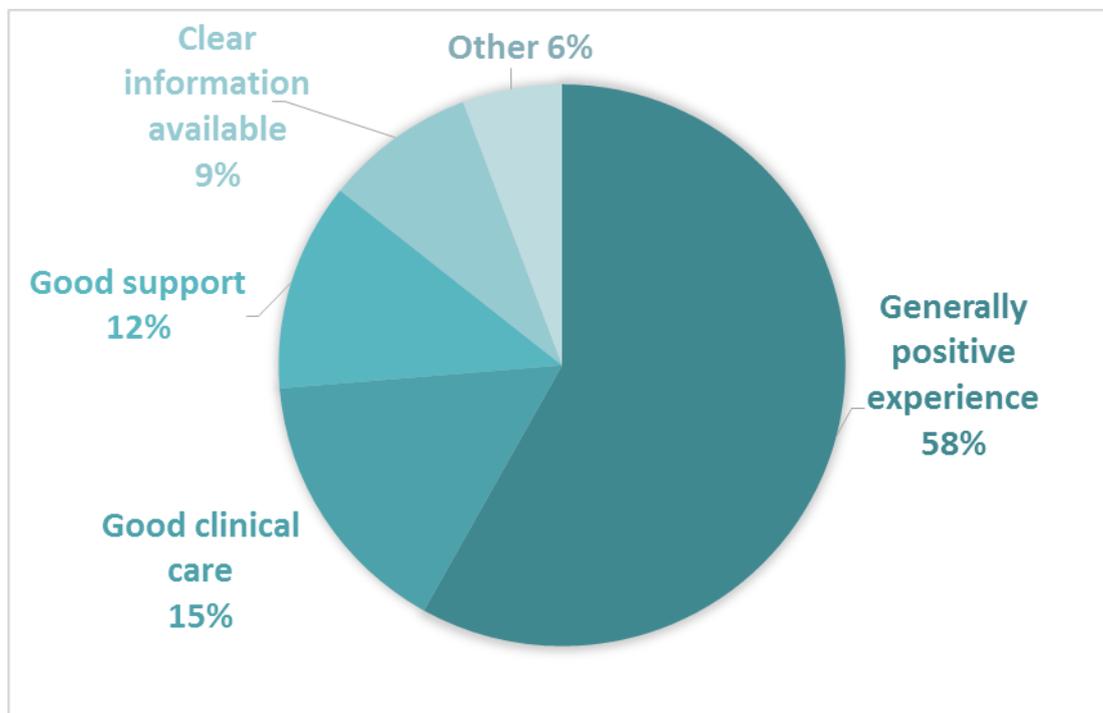


Figure 11 Positive subthemes for Comment Box 5 – The day patient/outpatient care you received

Negative

Of the negative sub-themes raised by participants about day patient and outpatient care they received (Comment Box 5), the most common related to fragmented care, waits and delays, and ineffective and unreliable processes (Figure 12).

Fragmented care was described by participants as a lack of continuity of care, with poor communication and access to notes between departments, hospitals and the GP. 289 negative comments were coded into sub-themes in Comment Box 5.

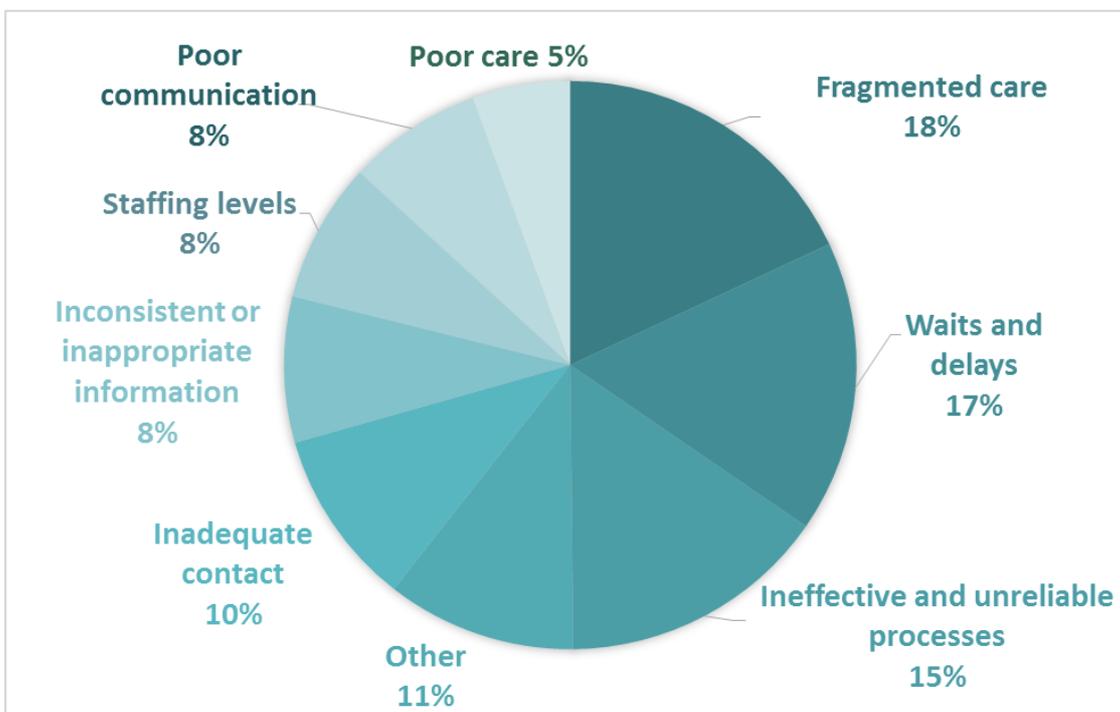


Figure 12 Negative subthemes for Comment Box 5 - The day patient/outpatient care you received

Chemotherapy/radiotherapy treatment (Comment Box 6)

Positive

The majority of positive comments for Comment Box 6 related to having a generally good experience, and receiving good support (Figure 13). 325 positive comments were coded into subthemes in Comment Box 6.

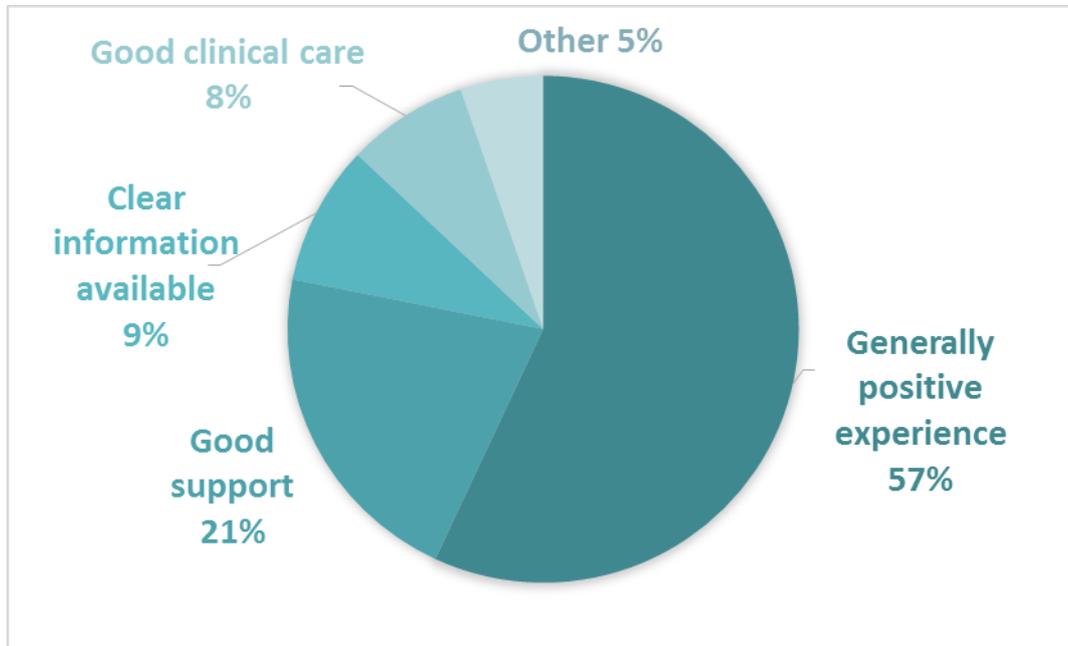


Figure 13 Positive subthemes for Comment Box 6 – Chemotherapy/Radiotherapy treatment

Negative

The breakdown of negative subthemes in Comment Box 6, showed that respondents had no single major issue with chemotherapy/radiotherapy treatment (Figure 14). The most common issues raised were with a lack of information, and lack of emotional support and responsiveness. Lack of information in the context of chemotherapy/radiotherapy was attributed to participants feeling that they had not been given sufficient information or explanation about potential problems with treatment or side effects, or about the long term effects of treatment. Lack of emotional support and responsiveness referred to staff solely focusing on the clinical aspects of care during chemotherapy/radiotherapy sessions, and not providing patients with any emotional support. 194 negative comments were coded into sub-themes in Comment Box 6.

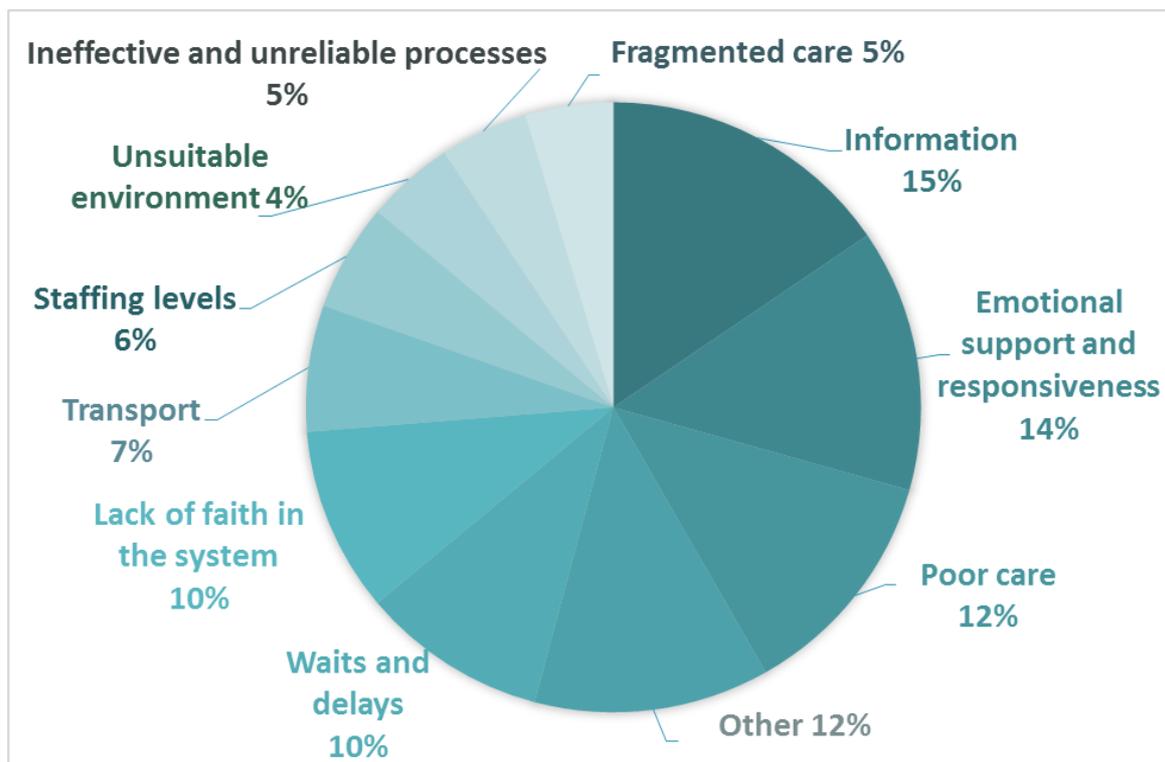


Figure 14 Negative subthemes for Comment Box 6 - Chemotherapy/ Radiotherapy treatment

Experience of cancer care (Comment Box 7)

Positive

847 positive comments were coded into subthemes in Comment Box 7, which asked patients to comment on anything else about their experiences of cancer care. The most common subthemes were having a generally positive experience, receiving good clinical care, and having good support (Figure 15).

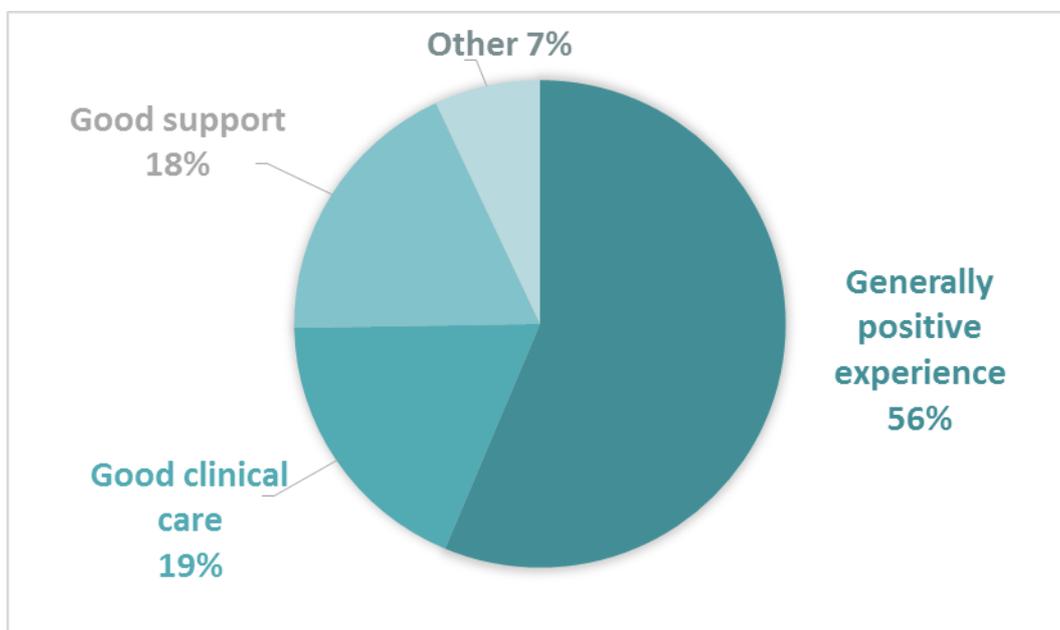


Figure 15 Positive subthemes for Comment Box 7 – Experience of cancer care

Negative

849 negative comments were coded into subthemes in Comment Box 7. The most common subthemes were receiving inadequate aftercare, and waits and delays (Figure 16). Patients described inadequate aftercare as receiving no care or follow-up after treatment, feeling alone and not receiving support from GPs and district nurses once hospital based treatment had ended.

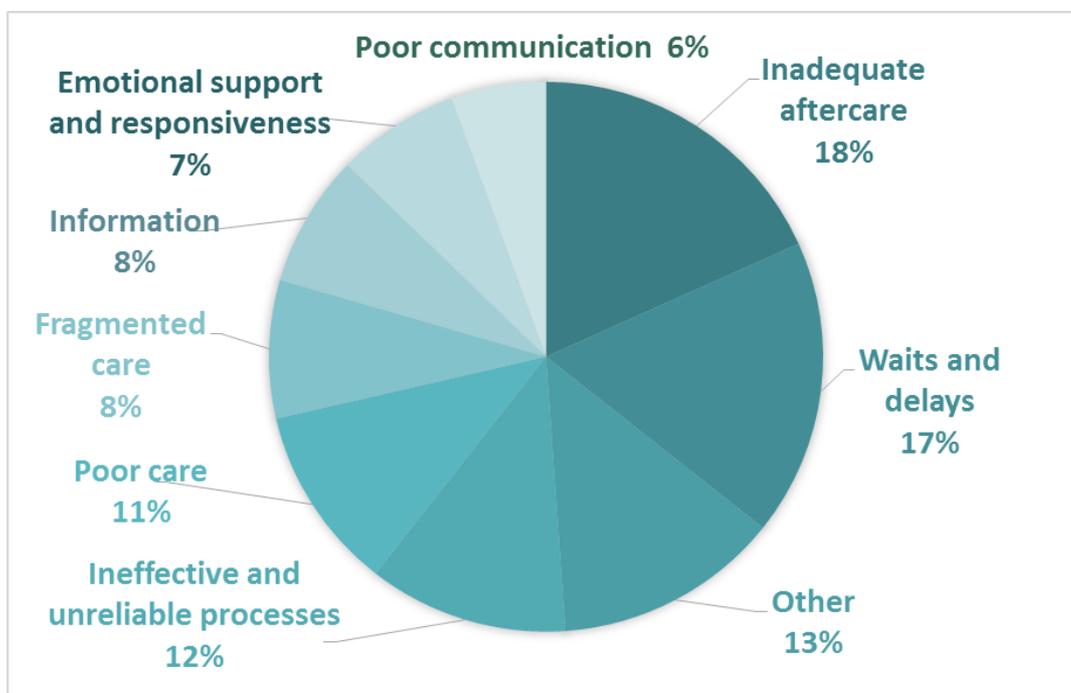


Figure 16 Negative subthemes for Comment Box 7 - Experience of cancer care

Discussion

Analysis of the free-text comments from the Scottish Cancer Patient Experience Survey provided a detailed insight into the importance, to people with cancer, of 'feeling confident within the system' and 'being treated as an individual'. This is the first survey of Scottish cancer patients which has included open-ended comments, and has added valuable information to our understanding of the many positives, but also the issues which patients encounter during their cancer journey. In total 2,663 (55%) respondents left at least one comment in the survey.

While participants gave more positive than negative comments, the positive comments were often generic, and lacked detail. The English (Wagland et al, 2015), London (Wiseman et al, 2015) and Welsh (Bracher, Wagland and Corner, 2014) Cancer Patient Experience Surveys also found that positive comments tended to lack detail of the specifics of favourable experiences. However, despite the lack of detail, several distinct themes emerged from the analysis of the positive comments, with many patients describing a good experience overall, and particularly valuing clear information, speedy and efficient processes, good support, good clinical care and feeling that they could put trust in the system.

Negative comments provided a much greater insight into the specific problems participants had encountered during their cancer care. The proportion of negative to positive comments (0.78:1) was greater in this survey than in either the Welsh (0.60:1) or London (0.51:1) surveys, however, this may be because the Scottish survey, unlike the London and Welsh surveys, did not specifically ask 'what patients found good about their cancer care'. Quantitative analysis of the tick-box questions in the Scottish Cancer Patient Experience Survey (Scottish Government and Macmillan, 2016) found that overall perceptions of care were very positive, with 94% of patients rating their care as '7' or higher on a scale from 0 (very poor) to 10 (very good).

However, analysis of the free-text comments highlights issues that are not revealed in the numerical analysis and provides greater understanding of the significant issues which have impacted on some aspects of patients' care. Participants may use many different criteria to arrive at a number to rate their care, however, the detail allowed in free-text comments provides respondents with the opportunity to express criticism over particular aspects of care which may not be captured in a single numerical rating. It is a well-documented feature of patient experience surveys that quantitative measures tend to be rated higher than qualitative surveys, where participants have the option to describe their concerns with the care they received (Williams, 1994). This is a discrete report of the interpretation of the free-text comments and has not compared or related findings from the free-text comments with the numerical findings.

Analysis of the free-text comments was inductive, and creation of the sub-themes was entirely driven by the data. The subthemes built up a picture of two key aspects of experience that were critically important, and generated an understanding of what feeling 'confident' and 'being treated as an individual' appear

to entail. They also illustrated how issues with structures and processes can impact negatively on patients' experiences. The importance of these themes is highlighted in both the negative and positive comments made by respondents.

The overwhelming impression from the free-text comments was that patients' experiences and impressions of cancer care were vulnerable to particular features of the way in which health care professionals communicated and the way in which health services were organised. If they were treated with kindness, and had clear expectations of what was going to happen to them, which were met, then they were positive about their care. However, if things did not go to plan, if they felt ignored, or if they started to doubt the competence of the people or system that was caring for them, they quickly became stressed and anxious and had a negative experience of care. The comments indicated that it was often aspects of the organisation of care which led patients to feel that nobody saw what was different about them, or treated them as a person with needs.

Responses to the free-text comment boxes in the survey gave a clear picture of the different aspects of care which influenced patients' feelings of confidence, or not feeling confident. Negative comments demonstrated that aspects of care at all points of cancer treatment could impact on feelings of security, from difficulties with being diagnosed with cancer, to inadequate aftercare. These negative incidents around quality and access to the system, affected patients' confidence in their cancer care.

The other major issue for participants was feeling that they were not being treated as an individual, with patients feeling isolated and alone within the system of care. Factors which contributed to patients feeling this way included poor communication, lack of involvement in decision making, lack of information and poor emotional support. The results of this survey highlight that patients wanted to feel that they were being treated respectfully and recognised as a person, yet instead in some cases felt depersonalised and alienated by the people who were caring for them.

Strengths and Limitations

The analysis of the free-text data within this survey followed a structured approach and was rigorous and thorough, reducing the risk of bias in analysis. Recognised techniques were used to structure the large data-set including using structural coding to allow analysis by comment box, and measuring code frequencies to give an indication of the prominence of different sub-themes (Namey et al, 2007). Reliability of the application of codes to raw data was monitored by an independent researcher. The large number of comments increased the likelihood that unusual circumstances would be captured in the data. The comment box questions were designed to ask patients about their experience rather than their satisfaction, asking participants to 'tell us' about their experience rather than to 'evaluate'. This removed the risks inherent in making assumptions about how patients evaluate satisfaction (Williams, 1994). The data was analysed by experienced qualitative researchers, independent from the NHS and Scottish Government, who had no preconceptions about the data or results.

A real strength of this survey was that free-text boxes were placed throughout the questionnaire, giving participants a chance to reflect and comment on different stages of the cancer journey. This enabled the analysis to focus on particular problems which arose at different points in the patients' treatment, and identified that different subthemes had prominence at different stages.

Although most of the issues within the subthemes were covered at some point in the tick-box questions in the survey, participants often brought up issues, unprompted, in the qualitative comments before they had arisen in the questionnaire. For example, although the first three comments boxes and their preceding quantitative questions didn't ask specific questions about continuity of care, or being treated as an individual, both came out strongly in participants' comments. The content of the comments boxes also reflected specific issues covered in the preceding questions. However, within the comments, participants gave much more depth and description about the issues.

A great richness of personal experience was conveyed through the comments in this survey. A report of this nature cannot do justice to these personal accounts due to the volume of comments. Clearly every comment is important, and condensing the number of comments of people who have had real lived experiences is by its very nature reductionist, and loses the powerful impact of multiple, deeply personal messages about patients' experiences. Nevertheless, the methods used to analyse the data attempted to capture the breadth and depth of difficulties patients experienced.

There is the risk of an inherent bias in free-text responses towards patients who are more literate, have English as a first language, and who do not have learning difficulties. A helpline was available for participants to seek assistance in completing the survey. However, we acknowledge that this method of gathering views on patient experience may not have been the most suitable for all potential participants.

Ideas for future consideration

Many of the comments marked as factual/neutral during the process of splitting comments into top level categories, related to participants commenting that the name of the hospital on the survey letter was not actually the hospital where they had received all their treatment. Many participants received treatment across multiple hospitals, across primary and secondary care, and in some cases, across several Health Boards. The London survey noted a similar problem, with many participants expressing confusion over how to complete the questionnaire given they were treated by multiple trusts (Wiseman et al, 2015). This issue was pre-empted in the Scottish survey by (i) removing the instruction to complete the survey only if the experience happened at the hospital named on the covering letter, and (ii) asking whether or not the treatment took place at the hospital named on the covering letter. However, the feedback from respondents suggests that even this solution does not allow participants to feedback on their care in as much detail as they would like.

Analysis of themes by comment box indicated that there were more negative than positive comments related to the lead up to diagnosis. Confusion over the role of the GP practice in the provision of aftercare also emerged as an issue. Future surveys could consider including a separate free-text comments box on the patient's experience of primary care to provide additional insight into these issues.

Cancer patient experience surveys in the UK have been designed to gather evidence on the experiences of care provided within the NHS, in order to inform NHS improvement strategies. Many SCPES participants indicated that cancer charities and other specialist services also had a role to play in their cancer experience. Patients' accounts in this survey indicate that their cancer care is often reliant on and directly affected by the availability and quality of these services, and as such, questions to gain more information about this relationship could be considered for future surveys.

As previously mentioned, positive statements about care were often generic and lacked detail. This may be because patients found nothing in particular to remark upon if the treatment they received met their expectations. However, understanding patients' expectations, and the specifics of what makes a good experience is important to preserve quality services. Future surveys could consider including questions to elicit the specifics of what patients value or find positive about their care.

Finally, further analysis of the coded qualitative dataset could look at whether sub-themes cluster into groups of co-occurring issues, and also analyse differences in sub-themes by demographic and clinical characteristics.

Conclusions

The inclusion of free-text comments in the first Scottish Cancer Patient Experience Survey has provided a rich and informative analysis of the experiences of people with cancer in Scotland, therefore enhancing the usability and relevance of the quantitative survey results. Following the publication of the Scottish Government's new Cancer Strategy in March 2016, this report provides meaningful evidence to underpin developments in care, coordination of services and research across the country, so as to achieve the ambitions of truly patient centred, safe and effective care for the growing number of people affected by cancer in Scotland.

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Appendix A Members of Survey Steering Group

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

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

Appendix B Data analysis process

Free-text comments were analysed by a team of three researchers with significant experience in qualitative analysis. The data were analysed using Thematic Analysis (Braun and Clarke, 2006), employing an inductive approach – coding and theme development were driven by the content of the free-text comments. The process involved identifying commonalities in the data, and searching and comparing the data to identify and record relationships and themes. In order to apply some structure to the large volume of data, the following steps were undertaken during analysis:

1. The complete data set was split into responses by comment box, creating seven data-sets.
2. For each of the individual comment box data-sets, one researcher familiarised themselves with the data by reading all the responses. During familiarisation, the researcher made a note of potential codes for that individual data-set by identifying recurring words or units of meaning (positive, negative or neutral observations). A second researcher familiarised themselves with a sample of the responses and the two researchers discussed and agreed the coding decisions.
3. The researcher sorted all responses in each individual data-set by allocating responses into the following top level categories (i) positive comment; (ii) negative comment; (iii) factual/neutral comment; (iv) irrelevant/miscellaneous comment; (v) both positive and negative comment. This process enabled the team to gain an overview of the nature and emphasis of comments made.
4. The same researcher then applied detailed codes to all responses in each individual data-set. Because the codes had been derived inductively from the responses to comment boxes, the coding sheet was different for each individual data-set. Comments were given as many codes as were appropriate to cover the content of the comment. In total, there were 174 codes across the seven comment boxes, for example speedy action; uncomfortable environment; rude or insensitive communication.
5. Each individual dataset was then split into separate sheets containing all comments for every code. All comments assigned to every code were then re-read to check for consistency of meaning within the code. During this process of constant comparison, where comments were not seen as a good 'fit' with the code, either the code was refined to reflect the comments within that code more meaningfully, or the comment was moved to an alternative code. At this stage, it emerged that an additional code for 'family history not taken seriously' was needed. The content for all comment boxes was then searched again, using the key words 'family' and 'history' and an additional coding sheet was created for relevant comments.
6. A second researcher then checked 5% of all comments for consistency in terms of splitting the data into top level categories, and coding decisions. Any

discrepancies or disagreements (of which there were only a small number) were discussed and codes adjusted as necessary.

7. Two researchers then worked together to identify similar codes across the seven comment boxes, in order to look for common themes across the whole data-set (i.e. across all stages of the cancer journey represented in the SCPES). The researchers amalgamated codes which shared similar meaning into sub-themes.
8. The research team then mapped subthemes into overarching themes which described the main issues highlighted in the data.

Appendix C Overview of Comments

A chi-square test indicated a significant difference in the proportion of positive to negative responses across the seven comment boxes ($\chi^2(6)=200.6$, $p<0.001$). Analysis of the adjusted standardised residuals showed that by far the largest negative residual was in Comment Box 1 suggesting respondents were proportionately less happy with the lead up to diagnosis (61% negative); and the largest positive residual was in Comment Box 3 suggesting respondents were proportionately more happy with the support they received (including from a clinical nurse specialist) (68% positive).

Top level category by comment box

Comment Box	Positive	Negative	Factual/neutral	Irrelevant/miscellaneous	Both positive and negative
1	369	571	597	22	114
2	338	260	242	12	39
3	499	232	76	8	83
4	478	293	88	144	117
5	292	153	46	143	44
6	197	105	65	211	48
7	355	355	94	45	226
Total	2,528	1,969	1,208	585	671

Appendix D Definitions of Negative Sub Themes

Sub Theme	Definition (Participants felt...)
Poor care	Inadequate management of pain and side effects, exposure to infection, problems with treatment, or being cared for by staff who did not have sufficient knowledge of cancer
Difficulty getting into the system	Multiple visits to GP with symptoms before being sent for diagnostic tests.
Inconsistent or inappropriate information	Given wrong, unclear or conflicting information
Lack of faith in the system	Not trusting the monitoring process would pick up deterioration in health
Inadequate aftercare	Inadequate care after treatment and confusion over who was responsible for care after treatment
Inadequate contact	Inadequate amount of contact with cancer specialists
Poor communication	Staff did not listen or treat patients with respect
Involvement and choice	Lack of involvement and choice in decision making about treatment
Emotional Support and Responsiveness	Insufficient emotional support and lack of contact with staff who could provide support
Information	Did not receive the amount or type of information required to meet individual needs
Family	Lack of consideration for family
Specific and unusual circumstances	Specific individual circumstances not taken into account
Unsuitable or uncomfortable environment	Problems with food, hygiene, noise levels, and uncomfortable surroundings
Transport	Problems with parking or transport to and from hospital
Staffing Levels	Not enough staff to meet patient demand
Privacy	Lack of privacy when receiving bad news or during procedures
Ineffective and unreliable processes	Administrative problems, especially with results letters and organising appointments
Waits and delays	Lengthy waits for results and appointments
Fragmented care	Many different departments involved in treatment, lack of continuity of care. No one in overall control.



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