Patient feedback and duration of treatment: A corpus-based analysis of written comments on cancer care in England

This study examines the relationship between the length of time since a patient received their first treatment for cancer and the feedback they give on that treatment. The analysis is based on a corpus of 214,340 written patient comments (14,403,694 words) relating to National Health Service (NHS) cancer care in England between 2015 and 2018. Patients are grouped according to treatment duration and compared in terms of the feedback ratings they gave, the themes of their positive and negative comments, and the keywords that characterise the language they use to provide qualitative evaluations of their experiences. We find that patient satisfaction rates remain relatively stable across the treatment duration groups, with patients generally indicating high levels of satisfaction. Patients likewise focus on a small number of core themes in their feedback, regardless of treatment duration, though there are differences in the extent to which certain themes are focused on by each group. Our analysis of keywords reveals differences in the focus of the comments, as well as the types of rhetorical strategies that patients (particularly those receiving treatment for longer periods) use not only to frame but also legitimise their feedback. The implications of the findings are discussed with respect to healthcare provision and feedback monitoring. We also discuss the value of combining a focus on content with form when working with non-linguist stakeholders, and reflect on the opportunities and challenges of convincing stakeholders of the value of using (corpus) linguistics methods to approach seemingly non-linguistic questions.

Keywords
Patient feedback, patient satisfaction, cancer care, NHS England, health communication, written comments

1. Introduction

Patient feedback provides a way for healthcare organisers to understand patients’ experiences of healthcare services so that the standards of those services can be monitored and improved. This study examines patient feedback on NHS cancer care services in England in the form of handwritten and typed (online) free-text comments provided as part of the national Cancer Patient Experience Survey. We focus on the influence of treatment duration (based on length of time from first treatment for cancer) on patients’ satisfaction rates, feedback themes, and the language used to provide feedback. In particular, we seek to answer the following questions: i.) How do experience and satisfaction rates compare across patients with differing treatment durations? ii.) What themes drive positive and negative feedback for patients with differing treatment durations? and iii.) What types of language are characteristic of feedback provided by patients with differing treatment durations (as characterised above)?

These research questions represent a mixture of the types of questions that were set to us by our stakeholder partner, NHS England & NHS Improvement (i. and ii.), which orient more to the content of the patient feedback, and the types of questions that we, as linguists, were more naturally inclined to ask (iii.), which focus more on the linguistic form of the feedback and how this may vary among different patient groups. This latter focus was not
raised by our stakeholder partner in the first instance but, rather, evolved from the original questions set to us as a result of our discussions with them. As well as providing new insight into how patient feedback varies according to treatment duration, this study will also demonstrate how a focus on content and linguistic form need not be mutually exclusive but can, instead, provide complementary insights in this context. Following this introduction, in the next section we introduce the genre of patient feedback in more detail. Section 3 outlines the study data and analytical approach. The findings are reported and discussed in Section 4, while Section 5 concludes the article by considering the implications of the findings and reflecting on the value and challenges of using of corpus linguistic methods when working with non-linguist stakeholders.

2. Patient feedback and NHS cancer care in England

Patient feedback has become an increasingly accepted measure of patient satisfaction rates in healthcare systems around the world, where patient satisfaction can be defined as ‘an individual patient or family visitor’s subjective perspective on medical services received […] adopted as one of the indicators of care quality’ (Tzeng and Yin, 2008: 122). For healthcare policy in England – the context under focus in this study – the importance placed on assessing and monitoring patients’ experiences of healthcare services has grown concomitantly with the increasing emphasis on patient-centredness (Coulter 2013), where patient involvement is viewed as a means through which providers can ensure that service improvements respond to patients’ needs (Richard, et al. 2010). At the same time, patient experiences have come to represent a valued form of healthcare systems knowledge which can help providers to ensure quality and patient-centredness in a context of rising demands and financial pressures in the UK (Cunningham and Wells, 2017). Embedding the results of patient satisfaction surveys into care delivery has also been shown to lead to improved understanding of patients’ expectations (Wolf et al., 2008), which in turn can result in improved health outcomes for patients (McGill, 2009).

The present study focuses, as noted, on patient feedback relating to cancer care provided by the NHS in England. Cancer is a leading cause of death globally (Ferlay et al., 2020), while in the UK one in two people will develop some form of cancer during their lifetime (Ahmad et al., 2015). Cancer remains a public health priority in the UK and across the globe, then, and understanding patients’ experiences of cancer care services is particularly important given that a considerable portion of the population is likely to require use of them at some point in their lives. Moreover, Richard et al. (2010) argue that evaluating patient satisfaction with respect to cancer care services is important due to the diversity of patients, patients’ complex care needs, and the increased survivorship of people diagnosed with cancer. This importance is recognised at an organisational level within the NHS in England, as in the other nations of the UK, where patient experience represents one of four key metrics used to rate cancer care services (Cancer Research UK, online).

Most existing studies of patient feedback have been undertaken by researchers working in health and medical disciplines. As a result, the majority of this research has focussed on issues such as the design of feedback mechanisms (Evans et al., 2007), the reliability of feedback data for assessing healthcare quality (Sitzia, 1999), the extent to which
insights from patient feedback actually leads to service improvements (Davies and Cleary, 2005), and how such insights might be implemented to improve services and clinical outcomes (Veloski et al., 2006). Such studies have thus tended to focus on the content of the feedback studied, with frequently reported drivers of feedback including the technical quality of care, accessibility to care, and the interpersonal and communication skills of practitioners (Greco et al., 2001; Gupta et al., 1993).

While such studies hold undoubted value for those responsible for designing care and monitoring and interpreting patient feedback, they also have limitations in terms of their data and methods of analysis. Concerning the data used, existing studies have tended to focus on a relatively small number of responses, usually in the hundreds (Lagu et al., 2010; López et al., 2012) and at the most in the tens of thousands (Raleigh et al., 2009), and so tend to offer fairly limited generalisability with respect to their findings. Another feature of existing research into patient feedback is the tendency to examine quantitative rather than qualitative responses (e.g. checkbox data). An advantage of checkbox data is that patients’ responses can be easily quantified to reveal feedback trends. However, a disadvantage of this type of data is that patients’ responses are constrained to the questions and checkbox options in the survey, meaning that patients have limited (if any) space to provide feedback about aspects of healthcare that might be important to them, but which are not covered by the questions in the survey.

Since most studies of patient feedback have been carried out within medical fields, existing research has tended to focus on what is said in the feedback, rather than how it is said. Although language plays a central role in studies of qualitative feedback, it has tended to be viewed as the medium through which information is exchanged (i.e. the feedback given), rather than being the object of study in its own right. As Mazanderani and Powell (2013: 97) observe, ‘[o] ne criticism frequently leveraged against research on patients’ experiences is that too little attention is paid to the issue of how these experiences, be they articulated in stories, brief quotes, images, or numbers, are constructed’. As a consequence, patients’ talk about healthcare is routinely treated as depicting some ‘reality’ of the healthcare services they represent. However, such representations do not offer a transparent window on the events or episodes of care being discussed in the feedback, but ‘emerge through particular socially and technologically mediated practices’ (ibid.).

Recent research has begun to address this previous lack of linguistic focus. For example, Baker et al. (2019) and Brookes and Baker (2017) used analysed 29 million-words of written patient feedback on NHS services in England. With the help of corpus linguistic methods, these studies were able to account for a larger and more representative set of patient comments than previous studies had, while the analyses moved beyond simply describing the content of the comments to consider the linguistic choices, and attendant discourses and rhetorical strategies, that patients drew upon in order to represent and evaluate their healthcare experiences. These studies provided detailed understanding of the language that patients use in their feedback, including how this language is shaped by social and technological factors (see also: Baker and Brookes 2021; Brookes and McEnery, 2017, 2020).

While the aforementioned linguistic studies of patient feedback focused on commented about English NHS services in general, in this article we adopt a narrower focus, working with a new dataset to examine linguistic choices made by patients in England receiving NHS treatment for cancer specifically. Compared to research on patient feedback in
general, feedback on cancer care services is relatively under-studied. Studies focusing on feedback on cancer care in the UK have reported that patients give generally favourable evaluations, with variables including waiting times, the availability and frequency of contact with healthcare providers, interpersonal aspects of care, patient-centred care, continuity of care and the physical environment in which care is provided (Cunningham and Wells, 2017; Malin et al., 2006; Richard et al., 2010).

The present study aims to develop on this existing body of research in a number of respects. First, most existing studies have focused on the experiences of patients with particular types of cancer, such as Damman et al.’s (2009) study of feedback on breast cancer care and Malin et al.’s (2006) focus on the experiences of patients with lung and colorectal cancer. The present study, on the other hand, is based on data representing patients with a wide range of types of cancer. Another, perhaps more important, feature which distinguishes the present study from existing research is that the data will allow us to explore the experiences of patients who are at different stages of treatment, where existing studies tended to focus on a single particular point, such as Booji et al.’s (2013) focus on feedback on hospital stays and Arora et al.’s (2011) study of patients’ experiences of follow-up care. Comparing feedback across time periods is important, though, as the process of being diagnosed and treated for cancer is ‘long and complicated, involving multiple stages of investigation and treatment, and multiple encounters with a variety of health professionals and services’ (Cunningham and Wells, 2008: 1). Finally, existing studies of feedback on cancer services have been carried out in disciplines outside of linguistics, which means that the content of such feedback is understood far better, in empirical terms at least, than the linguistic form that such feedback takes. Yet, as noted above, understanding not only what feedback says but also how it is said can provide insight into both patients’ priorities and the rhetorical strategies they use to express these and provide their evaluations of services. The data and analytical approach taken in this study are introduced in the next section.

3. Methodology

3.1. Data

The data analysed in this study is a specialised corpus containing written feedback on cancer care provided by respondents to the England Cancer Patient Experience Survey (CPES). Responses were given both online and through pen-and-paper forms, with the latter subsequently digitised by the NHS to render it amenable to computational analysis. The CPES form allows patients to provide both quantitative and qualitative feedback. The quantitative component asks respondents, ‘Overall, how would you rate your care?’, to which they can respond by providing a score between 0 and 10, where at one end of the spectrum a score of 0 indicates a very negative evaluation and, at the other end of the scale, a score of 10 indicates a very positive evaluation. Respondents then had the opportunity to describe their experiences and explain the score they gave by providing qualitative feedback across three free-text boxes. These free-text boxes are preceded by the following questions: ‘was there anything particularly good about your NHS cancer care?’, ‘was there anything that could have been improved?’ and ‘any other comments?’. For the purposes of this study, each
‘comment’ contains the responses to all three of these questions together, which correspond to comment ‘segments’; respectively, a positive segment, a negative segment, and an additional segment. Our corpus comprises free-text comments provided in response to these questions; in particular, it contains 214,340 responses (14,403,694 words), relating to hospitals across England, and provided between 2015 and 2018. NHS England & NHS Improvement made this data available to us as part of a formal collaboration, in which the organisation set us a series of questions to answer about the feedback.

To compare comments provided by patients at different points, we used metadata to divide our corpus according to patients’ self-disclosed treatment duration at the time of submitting their feedback (this is requested in a dedicated field within the feedback form). This allowed us to group the responses into the following three broad categories: under 1 year; 1-5 years; and over 5 years. Table 1 gives a breakdown of the number of comments, words and average words per comment for each category. Note that not all patients answered this question, while some indicated that they did not know/couldn’t remember how long they’d received treatment for. We excluded these cases from our analysis. As such, the numbers in Table 1 do not correspond exactly to the total number of comments and words in our corpus.

Table 1: Breakdown of comments and words, according to duration of treatment.

<table>
<thead>
<tr>
<th>Duration of treatment</th>
<th>Number of comments</th>
<th>Words</th>
<th>Average words per comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 1 year</td>
<td>128,804</td>
<td>8,866,673</td>
<td>68.84</td>
</tr>
<tr>
<td>1-5 years</td>
<td>59,577</td>
<td>3,960,335</td>
<td>66.50</td>
</tr>
<tr>
<td>Over 5 years</td>
<td>16,390</td>
<td>1,049,834</td>
<td>64.05</td>
</tr>
</tbody>
</table>

As this table indicates, the majority of the comments in our corpus represent the experiences and perspectives of patients who have received under one year of treatment (128,804 comments), with this group providing over twice as many comments as patients who have received between 1 and 5 years of treatment (59,577 comments). Meanwhile, we have the smallest amount of data for patients who have received over 5 years of treatment (16,390 comments). Despite these differences, the length of time a patient spends in treatment does not appear to strongly influence the length of the feedback they provide, which reduced slightly the longer patients received treatment, but only by an average of a couple of words between each category.

We should note at this point that our corpus of written comments is imbalanced in terms of the extent to which different demographic groups are represented within it. For example, 87.09% of the comments in our corpus were provided by patients who self-reported as White English/Welsh/Scottish/Northern Irish. Regarding sexuality, people who identified as being from LGBTQ+ backgrounds make up just 1% of respondents who provided a comment, while people who speak English as an additional language contributed 3.5% of the comments in our data. For this study, we have gathered all available feedback in order to achieve as comprehensive coverage of patients as possible, though it is important to bear this skew in mind.
3.2. Analytical approach

The corpus was mounted on and analysed using CQPweb (Hardie, 2012). To answer Research Question (i.), *How do satisfaction rates compare across patients with differing treatment durations?*, we focused on patients’ quantitative responses, comparing the distribution of scores between 0 and 10 across the treatment duration categories in Table 1.

To answer Research Question (ii.), *What themes drive positive and negative feedback for patients with differing treatment durations?*, we carried out qualitative thematic analysis of a random sample of 100 positive comment segments and 100 negative comment segments for each treatment duration category. Specifically, we thematically coded the reasons that patients gave for their positive and negative evaluations. For this, we adopted an inductive approach, with the development of codes being driven by the content of the comments themselves. Codes were checked by both authors to ensure consistency and problematic cases were discussed until both authors reached an agreement on the code(s) eventually applied. We experimented with different numbers of comment segments for this part of the analysis and found that 100 comments were sufficient for us to reach a saturation of themes, with the most prominent themes also becoming visible by this point. Comments that contained no explicit evaluation (i.e., which provided ostensibly factual or neutral accounts) were excluded from the sample, as were vague comments from which no specific theme of evaluation could be ascertained (e.g., ‘Everyone was very good and I was very pleased.’). Comments were assigned as many codes as was necessary to reflect the themes in the comment.

To answer Research Question (iii.), *What types of language are characteristic of feedback provided by patients with differing treatment durations?*, we carried out a keyword analysis by comparing comments from patients in the under 1 year category against those from patients who received treatment for 1 year or more (including those in the over 5 years category), and vice versa. Our decision to group patients in the over 1 year and over 5 years categories together for this part of the analysis was motivated by the fact that we originally analysed these groups separately, obtaining keywords for them by comparing their respective sets of comments against the rest of the data. However, there was considerable overlap between these sets of keywords (47 of the top 50, ranked by log-likelihood (Dunning 1993)), therefore we decided to group these together. This part of the analysis is therefore based on two sets of keywords – one for patients with under 1 year of treatment and the other for patients with 1 year of treatment or more – obtained by comparing either set of comments against the other. We then ranked each set of keywords by log-likelihood score and qualitatively analysed the top 30 for each. This qualitative analysis was based on 100 randomly selected concordance lines of each keyword, and broadly aimed to identify what the uses of the keywords revealed in terms of not only the themes of the feedback but also the perspectives that patients adopted on those themes and the rhetorical strategies they used to provide evaluations.

4. Results and discussion

4.1. How do satisfaction rates compare across patients with differing treatment durations?
The first part of our analysis compares the quantitative scores provided by patients who have received treatment for cancer for differing lengths of time. The proportions of patients giving each score, between 0 and 10, is shown in Table 2. We should note that these scores do not provide a comprehensive picture of all feedback provided during the period under study, but specifically those scores given by patients who also provided free text comments in addition to their quantitative ratings.

Table 2: Proportions of satisfaction ratings (0-10) given by patients according to duration of treatment (expressed as percentages).

<table>
<thead>
<tr>
<th>Rating</th>
<th>Duration of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Under 1 year</td>
</tr>
<tr>
<td>0</td>
<td>0.14%</td>
</tr>
<tr>
<td>1</td>
<td>0.23%</td>
</tr>
<tr>
<td>2</td>
<td>0.26%</td>
</tr>
<tr>
<td>3</td>
<td>0.45%</td>
</tr>
<tr>
<td>4</td>
<td>0.70%</td>
</tr>
<tr>
<td>5</td>
<td>1.80%</td>
</tr>
<tr>
<td>6</td>
<td>2.27%</td>
</tr>
<tr>
<td>7</td>
<td>6.45%</td>
</tr>
<tr>
<td>8</td>
<td>18.56%</td>
</tr>
<tr>
<td>9</td>
<td>29.42%</td>
</tr>
<tr>
<td>10</td>
<td>39.71%</td>
</tr>
</tbody>
</table>

As this table shows, the proportions of patients giving each rating are broadly similar, regardless of the length of time that patients have been receiving treatment at the point at which they provide feedback. In all cases, the proportion of patients consistently rises along with the rating, with the lowest rating of 0 being given by the fewest patients and the highest rating of 10 being given by the most. Across all categories, the jumps in the proportions of patients giving each score are very small from 0 through to 4, being less than 1% in each case. There is then a slightly sharper increase between those giving 4s and 5s across all categories, with a rise of over 1% in each category. However, the sharpest rises for each category come between the ratings of 7 through to 10, across the board.

Overall, then, the proportions of patients giving each score are similar across all categories, which suggests that duration of treatment does not strongly influence satisfaction rates, and that the vast majority of patients across all categories gave very positive feedback, with scores of at least 8: under 1 year (87.69%), 1-5 years (86.27%), over 5 years (86.36%). However, we should note that the largest differences between the categories also came in the proportions of patients who gave the very highest score of 10, where the 39.71% of patients with under 1 year of treatment who gave the highest score of 10 is approximately four percent higher than the proportions giving this score in both of the other categories. Therefore, while the feedback is overwhelmingly positive for patients regardless of duration of
treatment, patients who have received treatment for less than one year are the most enthusiastic, being most likely of all the groups to give the highest score of 10.

4.2. What themes drive positive and negative feedback for patients with differing treatment durations?

Although the ratings are, as we have seen, fairly comparable across the treatment duration groups, this does not necessarily mean that the themes that characterise and drive the feedback are the same across these groups. Therefore, the next part of our analysis considers what themes drive the positive and negative feedback given by patients who have received treatment for differing durations. To consider this, we manually analysed and thematically coded a sample of 100 positive comment segments and 100 negative comment segments for each group of patients (i.e., under one year of treatment, 1-5 years, over 5 years). To aid comparison, we present our analysis of all the comments for each group together. Starting with the positive comments, Table 3 gives a breakdown of the themes of patients’ positive evaluations. The group most likely to mention each theme in their feedback is highlighted in bold. Note that, as multiple codes could be applied to a single comment, the percentages in each column total more than 100.

<table>
<thead>
<tr>
<th>Category</th>
<th>Under 1 year</th>
<th>1-5 years</th>
<th>Over 5 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff interpersonal skills</td>
<td>40%</td>
<td>44%</td>
<td>55%</td>
</tr>
<tr>
<td>Speed/efficiency</td>
<td>31%</td>
<td>20%</td>
<td>8%</td>
</tr>
<tr>
<td>Communication</td>
<td>25%</td>
<td>17%</td>
<td>9%</td>
</tr>
<tr>
<td>Staff technical competence</td>
<td>9%</td>
<td>25%</td>
<td>10%</td>
</tr>
<tr>
<td>Treatment</td>
<td>13%</td>
<td>20%</td>
<td>7%</td>
</tr>
<tr>
<td>Staff being hard-working</td>
<td>9%</td>
<td>9%</td>
<td>6%</td>
</tr>
<tr>
<td>System and administration</td>
<td>6%</td>
<td>9%</td>
<td>8%</td>
</tr>
<tr>
<td>Care co-ordination</td>
<td>0%</td>
<td>5%</td>
<td>13%</td>
</tr>
<tr>
<td>Care being free</td>
<td>0%</td>
<td>8%</td>
<td>8%</td>
</tr>
<tr>
<td>Aftercare</td>
<td>1%</td>
<td>5%</td>
<td>9%</td>
</tr>
<tr>
<td>Facilities</td>
<td>8%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Given sufficient time at appointments</td>
<td>1%</td>
<td>2%</td>
<td>4%</td>
</tr>
</tbody>
</table>

The first feature of this table that we want to note is that the range of drivers of positive feedback is relatively narrow, with a lot of overlap between the groups. This suggests that patients tend, in general, to base their comments on similar themes in their positive feedback, regardless of the duration of their treatment, with the most common theme underpinning positive evaluation being the same for all groups: staff interpersonal skills.

However, in some respects the groups can be distinguished in terms of the extent to which certain themes characterise the praise they give. For example, while speed and efficiency are important to all patients, this seems to be a priority in particular for patients
during the initial stages of their treatment. In particular, while speed and efficiency drove 31% of positive evaluations by patients within the first year of their treatment, this theme was visible in 20% of positive evaluations given by patients with 1-5 years of treatment and just 8% of patients who have received treatment for over 5 years. This could reflect the particular importance of timing and speed at the beginning of cancer treatment, specifically in regard to the identification and diagnosis of cancer. Indeed, this is indicated in the comments about speed and efficiency from this group. Note that examples shown were deemed to be representative of the manifestation of given themes.

1) The diagnosis and treatment was very fast. I was impressed.  
   (Under 1 year)

We can observe a similar pattern in relation to communication, with patients within the first year of treatment praising this aspect of service the most (31%) followed by patients with between 1 and 5 years of treatment (17%) and then least of all by patients who have received treatment for over 5 years (9%). This pattern can again be related to diagnosis, as patients in the under 1 year group praised diagnoses that were communicated in a sensitive manner, while they and patients in the 1-5 years group also praised staff for communicating clearly what treatment will entail, including to patients’ families.

2) My diagnosis was given sensitively and my pre operation tests and operation were arranged.  
   (Under 1 year)

3) Dr [anon] was very good, from when he told me the diagnosis to when he left. He explained my treatment to me and my relatives. He even stayed late one night to speak to my daughter. I always felt he was doing the best possible for me.  
   (1-5 years)

One feedback theme – facilities – featured only in sample of comments from the under 1 year group (8%). One explanation for this could be that patients in the other groups are more familiar with the facilities when writing their comments, having likely made multiple visits to the care site in question. On the other hand, many of the patients within the first year of treatment seem to be providing feedback based on their very first visit to a provider, and so may be encountering the facilities for the very first time.

4) [anon] Hospital was a very friendly and caring hospital. I particularly felt comfortable being able to go to the café and wait for my appointment - I am a very anxious person and this has made a lot of difference to me.  
   (Under 1 year)

Moving onto the patients who received between 1 and 5 years of treatment, above we saw how this group provided positive feedback when they felt that their treatment was well explained to them. Inspecting Table 3 further, we can also see that this group was particularly
likely to praise the standard of the treatment itself. While treatment standards are, of course, likely to represent an important concern for patients at all stages of treatment, this are commented on most often by patients in the 1-5 years group (20% vs 13% of under 1 year group and 7% of the over 5 years group). One explanation for this could be that this group have, by this point, long since received their diagnosis and are by now familiar with the facilities, so these themes – which occupied a larger proportion of the positive comments from patients with under 1 year of treatment – make way for greater focus on the treatment itself. This could also help to explain why the related theme of staff members’ technical skills are focussed on proportionally more by this group than the others (25% vs 9% of the under 1 year group and 10% of the over 5 years group). Examples of both themes are given below.

5) The operation was excellent. The times I have seen my surgeon subsequently (and my designated cancer nurse) have been very helpful and positive.  
   (1-5 years)

6) Every possible option was provided, culminating in an operation to remove my spleen, very successfully by a skilled surgeon.  
   (1-5 years)

Another theme that was particularly prominent in comments from the 1-5 years group was the cost of care – specifically, praise that care was provided for free on the NHS. We identified this theme in 8% of the sample of comments from the 1-5 years group and in the same number of comments in the over 5 years sample. On the other hand, this theme did not emerge at all in the sample of positive feedback from patients in their first year of treatment. One explanation for this difference could be that the value of treatment becomes more obvious to patients the longer that they receive treatment, as the involvement of various individuals, departments, and potentially even hospitals, becomes more visible to patients the longer they receive treatment.

7) Your cancer care staff from the surgeon, post-op nursing care and chemo consultant and supporting staff were all excellent. I feel so blessed to have received such expert treatment and care, and for free! Couldn't pay for anything better anywhere in the world!  
   (1-5 years)

Moving on to the sample of patients who have received over 5 years of treatment and the first feature we want to observe is that patients in this group were the most likely to praise staff for their interpersonal skills. While this theme is, as noted, clearly important to patients at all stages of treatment, being the most frequent theme across all samples of positive feedback analysed, it appears nevertheless to drive positive evaluations more as time goes on. An explanation for this could be that patients establish stronger relationships with staff members over the course of their treatment. Indeed, patients in the over 5 years category positively evaluated staff members for remembering their names and praised staff for ‘always’ being polite and compassionate.
8) The staff, nurses and doctors are always cheerful and kind.  
(Over 5 years)

9) They remember my name and will always ask how I am and have a chat. This is so important as I have to attend regularly and it makes unpleasant treatment more bearable.  
(Over 5 years)

The involvement of multiple staff members, departments and hospitals over time, which may, as we have discussed, garner a greater appreciation of the value of treatment in patients in the over 5 years, also helps to explain why patients in this group were most likely to praise treatment that was well co-ordinated between different individuals, departments and sites (13%). This was also commented upon, albeit less frequently, by patients in the 1-5 years group (5%) but not at all in our sample of comments from patients within the first year of treatment.

10) Good communication is maintained between teams at the two hospitals, this includes the renal consultant at [anon].  
(Over 5 years)

Patients in the 1-5 and over 5 years groups also shared a focus on the quality of aftercare (5% and 9%, respectively) – a theme which was visible in just 1% of the comments in the under 1 year sample. This feature may reflect the fact that patients who have received treatment for longer durations are more likely to be at the stage where they have received aftercare, or at least have a better sense of what aftercare entails, having received treatment for longer.

11) Follow-up care to check if the cancer has returned have been excellent.  
(Over 5 years)

Another area where differences are small, but which is worth commenting on nonetheless, is in comments where patients mention that they feel they have been given sufficient time with practitioners. This was mentioned in 4% of the positive comments from patients with over 5 years of treatment, in 2% of comments from patients with 1-5 years of treatment, and 1% of our sample of comments from patients with under 1 year of treatment.

12) Clinic appointments are always worth the wait as patients are always given the time they need which is very important.  
(Over 5 years)

Not all drivers of positive feedback exhibited big differences between the groups, though. In particular, as well as rating staff positively for their interpersonal skills, patients at all treatment durations also praised staff for being hard working (9% for both the under 1 year and 1-5 years groups, and 6% of the over 5 years group).
[anon] Hospital couldn't do enough for you. They all worked hard to make sure you were well looked after and comfortable.

(Under 1 year)

Similarly, the theme of system and administration was raised in 6% of the sample of positive comments from patients with under 1 year of treatment, in 9% of cases for the 1-5 years group and 8% of the over 5 years groups.

The administration was very efficient and well organised. I felt taken care of.

(Over 5 years)

Having compared patients of different treatment durations in terms of the themes that constitute their positive feedback, we then turned our attention to the negative comments to see whether the same patterns observed in relation to praise also applied to criticism. As in the analysis above, we have provided a summary of these complaints for each group, with the group most likely to give each complaint again highlighted in bold.

Table 4: Themes of negative evaluation when patients are grouped by duration of treatment.

<table>
<thead>
<tr>
<th>Category</th>
<th>Under 1 year</th>
<th>1-5 years</th>
<th>Over 5 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waits at appointments</td>
<td>22%</td>
<td>13%</td>
<td>9%</td>
</tr>
<tr>
<td>Waits for treatment</td>
<td>6%</td>
<td>20%</td>
<td>18%</td>
</tr>
<tr>
<td>Communication</td>
<td>21%</td>
<td>7%</td>
<td>6%</td>
</tr>
<tr>
<td>Staff shortages</td>
<td>4%</td>
<td>14%</td>
<td>14%</td>
</tr>
<tr>
<td>Care co-ordination</td>
<td>0%</td>
<td>12%</td>
<td>19%</td>
</tr>
<tr>
<td>Waits for test results</td>
<td>6%</td>
<td>11%</td>
<td>13%</td>
</tr>
<tr>
<td>Treatment spread across different locations</td>
<td>1%</td>
<td>11%</td>
<td>13%</td>
</tr>
<tr>
<td>Waits and delays at pharmacy</td>
<td>13%</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>Staff interpersonal skills</td>
<td>10%</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>Facilities</td>
<td>10%</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Aftercare</td>
<td>1%</td>
<td>9%</td>
<td>4%</td>
</tr>
<tr>
<td>Delayed/missed diagnosis</td>
<td>7%</td>
<td>5%</td>
<td>1%</td>
</tr>
<tr>
<td>System and administration</td>
<td>11%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Treatment</td>
<td>8%</td>
<td>2%</td>
<td>0%</td>
</tr>
<tr>
<td>Not given sufficient time at appointments</td>
<td>5%</td>
<td>1%</td>
<td>0%</td>
</tr>
<tr>
<td>Staff technical competence</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Parking facilities</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Food</td>
<td>2%</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

First, we want to note that some of the patterns evident in this table are consistent with the positive comments analysed above and, in this sense, can be interpreted as mirroring the positive feedback given by patients at different treatment stages. For example, we found that, as with the positive comments, patients within the first year of treatment were most likely to
raise the theme of communication in their negative feedback (21%). Again, in most cases this related to the manner in which diagnoses were communicated to patients.

15) The manner in which I was told about my diagnosis. It was told in a cold, insensitive manner and left me feeling 'what is the point'?

(Under 1 year)

Relatedly, patients in the under 1 year group were also most likely to raise the theme of diagnosis in complaints that their diagnosis of cancer was originally missed or delayed (7%, compared to 5% of the 1-5 years group and 1% of the over 5 years group).

16) … the test results were re-examined and there was an ill defined opacity which was missed! By the time the correct diagnosis was made, the cancer had spread to other areas.

(Under 1 year)

Patients with under 1 year of treatment were also most likely, as they were with their positive comments, to base negative feedback on a single episode of treatment. This gives rise to complaints around the theme of treatment effectiveness (8%, compared to 2% of the 1-5 years group and no cases at all in the over 5 years group), with particular focus on medication, including comments about the wrong medication being given, requested medication being denied, and pain relief medication being ineffective which leads to treatment being painful.

17) I detected the wrong treatment plan was printed for my third phase of chemotherapy. An early apology was made. A nurse nearly gave me an incorrect does of medicine until I discusses it with her.

(Under 1 year)

18) Family GP refused to give my monthly injection of somatuline autogel saying he didn't have the resources (bull).

(Under 1 year)

19) Only complaint was the care on ward, wounds not checked till next day or when I asked someone to look at them, pain relief was inadequate!

(Under 1 year)

Likewise, these patients were likely than others to comment negatively on the perceived technical competence of staff (4% compared to no cases in the other groups).

20) One was a contract nurse who I think was incompetent, she didn't seem to know what she was doing when she was removing my drains. It was painful and when she dressed the drains wound, she compromised my sterile post operation dressings.

(Under 1 year)
Other complaints that were most prevalent among patients with under 1 year of treatment which were based on a single treatment experience related to the amount of time given at appointments (5% vs. 1% of patients with 1-5 years of treatment and none in the over 5 years group). This represents something of an inverse of the positive samples, where time given at appointments was a theme associated with praise given by patients with over 5 years of treatment.

21) I feel that time spent with the oncologist has felt rushed during some of my appointments.  
   (Under 1 year)

Complaints about short appointment times could also be linked to the fact that this group of patients also complained about issues relating to communication, which may result in interactions appearing more abrupt. Another theme that was more common in complaints from the under 1 year sample was food, particularly that was provided during a stay in hospital (2% vs. none in the other two groups).

22) Poor food - cottage pie midday and evening no other choice except eggs which I was not allowed on warfarin.  
   (Under 1 year)

In the previous section, we saw how patients with under 1 year of treatment were more likely than the other groups to praise aspects of service provision that are evident from a single (the first) visit to a provider. This is also true of the criticisms, with this group being more likely than the others to raise the theme of facilities in their complaints (10% vs. 2% in both of the other groups), including parking facilities (4% vs. no cases in the other groups).

23) I had a spell of 2 1/2 weeks in the [anon] hospital, recently when I underwent high dose chemotherapy and a stem cell transplant (oncologist) for most of my stay I was on a ward rather than in a private room which I feel had a detrimental effect on my recovery due to picking up an infection. The situation didn't private me with any privately or dignity at a time when I was the most ill. I had ever been, I think patients undergoing such transplant and treatment should be given privacy in their own room to make the experience less painful.  
   (Under 1 year)

24) The only real problem was parking at the hospital. Few spaces available at appointment time. Get rid of parking eye, the money making machine.  
   (Under 1 year)

On the other hand, and again consistent with the positive feedback analysed earlier, patients who have received treatment for longer (1-5 years and over 5 years) were more likely to provide negative feedback about particular aspects of care which involve multiple
individuals, providers sites of care. For example, complaints about treatment being provided across multiple sites – particularly in locations that are far from where patients live – were given by 11% of patients from the 1-5 years group and 13% of the over 5 years group but just 1% of the under 1 year group.

25) It would be helpful if all testing/treatments could be at the same hospital. I am currently going to four different hospitals.

(1-5 years)

26) Over the 20 years I have been coping with the cancer, I have attended 3 different hospitals for treatment. […] One hospital, [anon], for all these treatments would have helped to reduce the very inconvenient and painful travelling I had to endure.

(Over 5 years)

Relatedly, these groups were also more likely to comment on a lack of effective care co-ordination, with this theme emerging in 19% of complaints from the over 5 years group, 12% of the 1-5 years group, but not at all in the under 1 year group.

27) Yes, because I have had a number of scans - on each occasion at my follow up meeting (probably 3 weeks later) the scans were never available. There seems to be no co-ordination between the scan been taken and arriving with the oncologist on time for patient visits.

(Over 5 years)

It is perhaps this experience of receiving care from multiple providers and across multiple sites which also leads to these groups being more likely to comment on perceived shortages in staff numbers. This complaint was made in 14% of complaints from both the 1-5 years and the over 5 years groups, and just 4% of the under 1 year sample.

28) More nursing staff, I think the department seems generally short staffed.

(1-5 years)

While patients with under 1 year of treatment were, as we have seen, more likely to complain about issues surrounding diagnosis, patients in the 1-5 years group were most likely to complain about issues relating to aftercare (9%), with such complaints being less likely to come from the over 5 years group (4%) and least common among the under 1 year sample (1%).


(1-5 years)

One pattern in Table 4 which could be viewed as inconsistent with the positive feedback analysed earlier is that staff interpersonal skills, while tending to motivate positive feedback
more among patients who experienced their first treatment a long time ago, tended to inform criticism slightly more from patients earlier on in their treatment (10% vs. 5% of the 1-5 years group and 3% of the over 5 years group). This could result from the tendency for patients in the under 1 year group to focus mostly on a single or small number of treatment episodes, where a single rude member of staff will loom larger in the feedback, with such individual cases being less influential in the more holistic kind of feedback given by patients further along the treatment pathway.

30) cancer inpatient wards were terrible, staff were rude, no time for you, moved you in the middle of the night, rude to your family. Would not like to think they were caring for me again.

(Under 1 year)

In the previous section, we saw how the theme of system and administration was fairly comparable in frequency across the positive feedback provided by the three groups. However, in the negative feedback, this theme was much more frequent in the sample of patients within their first year of treatment (11%) relative to the other groups (both 1%). Criticisms of system and administration in the under 1 year sample consistently focused on a single incident, typically relating to the organisation of appointments. Thus, we could interpret this trend as resulting from the same tendency which accounts for the above-noted pattern relating to criticism around staff interpersonal skills; namely, that the focus on a single or small number of treatment episodes in the feedback from patients with under 1 year of treatment results in single errors, in this case relating to system and administration, playing a bigger role in the feedback.

The biggest difference between the positive comments analysed earlier and the complaints represented in Table 4 concerns the theme of waiting. Waits tend to be raised in negative feedback more than positive feedback, with praise for speed and efficiency in general being present but less specific. Complaints about waits in the samples analysed can be grouped into four sub-categories: Waits at appointments; Waits for treatment; Waits for test results; and Waits and delays at pharmacy. Taken together, complaints around waiting represented the most prevalent theme for each group. Comparing the treatment duration groups, we see that waits at pharmacy and on the day of appointments are more common in patients with under 1 year of treatment. In particular, this group complained about waits at appointments 22% of the time (compared to 13% of the 1-5 years group and 9% of the over 5 years group) and complained about waits and delays at pharmacy in 13% of cases (compared to 5% for both of the other groups). Again, these trends are consistent with the tendency for this group to focus on a small number and often single episode of treatment.

31) The waiting time for treatment in unit could sometimes be better.

(Under 1 year)

32) My stay in hospital [anon] Surgery would have improved by quicker and smarter release from hospital (prescription and pharmacy held these up).

(Under 1 year)
Meanwhile, complaints about waits for treatment, for example to receive appointments, are more common amongst both the 1-5 years group (20%) and the over 5 years group (18%) than the under 1 year group (6%).

33) I have been on a waiting list for reconstruction for 6 months and have now been told it could be another 6 months before I get my surgery, this does not help my mental state as its so much harder to try and move on. (1-5 years)

Finally, the theme of waits for test results was also mentioned more often in negative feedback from patients who are further along in their treatment, with the proportion of patients giving this particular complaint rising as we move through the groups: Under 1 year: 6%; 1-5 years: 11%; Over 5 years: 13%.

34) Yes test results take too long to come back from labs. (Over 5 years)

Overall, then, while patients in their first year of treatment tend to complain more about delays on the day of treatment (i.e. at appointments and pharmacy), patients further into their treatment focus comparatively more on delays spanning longer stretches of time (i.e. for appointments and test results).

The analysis reported in this section has gestured to a number of thematic patterns relating to the positive and negative feedback given by patients at different points over the course of their treatment. In focusing on the themes of the feedback, our analysis has oriented more to the content of the comments rather than their linguistic form (i.e., it has focused more on what is said than how it is said). However, our understanding of the relationship between treatment duration and feedback can, as we have argued, be further enriched by looking at the types of language and rhetorical strategies that patients use to frame their evaluations of these themes. We provide such an analysis in the next section.

4.3. What types of language are characteristic of feedback provided by patients with differing treatment durations?

As described in Section 3, to answer our third Research Question we focus on language that is characteristic of comments provided by patients with differing treatment durations by comparing sets of comments against each other using the keywords technique. As also noted in that section, our initial analysis considered the three patient groups separately, however there was a large degree of overlap in the keywords for the 1-5 years and over 5 years groups. Therefore, we merged these groups together for this part of the analysis, which resulted in two sets of comments: i.) under 1 year, and ii.) 1 year and over. We generated keywords for both of these sets of comments by comparing each against the other. Beginning with the under 1 year group, Table 5 gives the top 30 keywords (ranked by log-likelihood) for this set of comments (positive and negative) when compared against comments from patients who received treatment for 1 year or more.
Table 5: Top 30 keywords for the under 1 year group compared to the 1 year and over group.

<table>
<thead>
<tr>
<th>Keyword</th>
<th>Under 1 year</th>
<th>1 year and over</th>
</tr>
</thead>
<tbody>
<tr>
<td>was</td>
<td>(208,899)</td>
<td>(22,503)</td>
</tr>
<tr>
<td>operation</td>
<td>(22,503)</td>
<td>(14,766)</td>
</tr>
<tr>
<td>were</td>
<td>(62,871)</td>
<td>(5,956)</td>
</tr>
<tr>
<td>radiotherapy</td>
<td>(13,668)</td>
<td>(10,347)</td>
</tr>
<tr>
<td>surgeon</td>
<td>(10,347)</td>
<td>(14,766)</td>
</tr>
<tr>
<td>surgery</td>
<td>(14,766)</td>
<td>(10,347)</td>
</tr>
<tr>
<td>did</td>
<td>(21,508)</td>
<td>(31,180)</td>
</tr>
<tr>
<td>after</td>
<td>(31,180)</td>
<td>(5,956)</td>
</tr>
<tr>
<td>biopsy</td>
<td>(5,956)</td>
<td>(22,503)</td>
</tr>
<tr>
<td>speed</td>
<td>(4,311)</td>
<td>(31,180)</td>
</tr>
<tr>
<td>quickly</td>
<td>(6,458)</td>
<td>(12,021)</td>
</tr>
<tr>
<td>had</td>
<td>(73,535)</td>
<td>(31,180)</td>
</tr>
<tr>
<td>quick</td>
<td>(3,727)</td>
<td>(5,956)</td>
</tr>
<tr>
<td>felt</td>
<td>(12,021)</td>
<td>(73,535)</td>
</tr>
<tr>
<td>weeks</td>
<td>(11,333)</td>
<td>(12,021)</td>
</tr>
<tr>
<td>Mr</td>
<td>(5,515)</td>
<td>(5,515)</td>
</tr>
<tr>
<td>night</td>
<td>(4,247)</td>
<td>(14,131)</td>
</tr>
<tr>
<td>impressed</td>
<td>(3,726)</td>
<td>(5,631)</td>
</tr>
<tr>
<td>thank</td>
<td>(14,131)</td>
<td>(5,631)</td>
</tr>
<tr>
<td>everything</td>
<td>(10,868)</td>
<td>(10,868)</td>
</tr>
<tr>
<td>discharge</td>
<td>(2,978)</td>
<td>(43,094)</td>
</tr>
<tr>
<td>from</td>
<td>(43,094)</td>
<td>(62,695)</td>
</tr>
<tr>
<td>me</td>
<td>(62,695)</td>
<td>(17,771)</td>
</tr>
<tr>
<td>I</td>
<td>(296,736)</td>
<td>(296,736)</td>
</tr>
<tr>
<td>recovery</td>
<td>(2,446)</td>
<td>(2,446)</td>
</tr>
<tr>
<td>days</td>
<td>(6,948)</td>
<td>(6,948)</td>
</tr>
<tr>
<td>mammogram</td>
<td>(2,329)</td>
<td>(2,329)</td>
</tr>
<tr>
<td>theatre</td>
<td>(1,276)</td>
<td>(1,276)</td>
</tr>
</tbody>
</table>

Compared to patients who have received treatment for a year or more, feedback provided by patients within their first year of treatment can be characterised in terms of the telling of narratives relating to a single episode of treatment or at least a small number of treatment episodes. These stories are characteristically located within the past, which explains the keyness of both the past continuous verb was and its plural equivalent, were, as well the past tense verbs did and had.

The narratives typically focus on a single operation or procedure, indicated in uses of the keywords operation, radiotherapy, surgery, biopsy and mammogram, where the operations took place (theatre), as well as events surrounding the procedure; namely, discharge and recovery. Other keywords tend to be used to locate the events in the narratives within time and to give a sense of the duration of the stay (weeks, night, days), or to otherwise sequentially arrange the events being recounted (after, from).

35) The only stressful time was on the day ward on the day of my operation. I was asked to attend at 7am and arrived 10 minutes early. The ward staff were in handover and 20 other patients, plus relatives had to wait in the corridor until 7.30am when the staff became available. There were no chairs to sit on and I began to feel very stressed and faint.

(Under 1 year)

36) I was sent home less than 18 hours after having been returned to the ward. I felt I should have been given more time to recover.

(Under 1 year)

There is also focus on the individuals who carry the procedures out, reflected in uses of the keywords, surgeon and the honorific Mr.

37) My CNS [anon] and surgeon Mr [anon] have been great to work with.

(Under 1 year)

There is a marked focus in this feedback, then, on operations and procedures and the staff who perform them. Yet as well as focusing on operations, the patients in this group also characteristically focused on the theme of communication, with the quotatives explained and told both key in this set of comments (notably, again these are both past-tense forms). This also helps to explain the keyness of everything, staff were praised for communication that was deemed by patients to be comprehensive.
38) The consultant surgeon was so kind and caring, I couldn't have asked for better. Mr [anon] explained everything very clearly, gave my husband and I as much time as we needed and made a difficult time easier to understand and accept.

(Under 1 year)

Another set of thematic keywords that is consistent with the analysis in the previous section relates to speed and efficiency (speed, quickly, quick), which was most prevalent in positive feedback from patients in the under 1 year group.

As well as focusing on individual staff members, the pronoun keywords me and I indicate a characteristic focus on the self in this feedback. The keyness of these items partly reflects the narrative style that is characteristic of comments in this group, where patients place themselves in their stories, for example as the recipient of procedures and diagnoses. These pronouns also reflect a greater emphasis on the disclosure of feelings and emotions, as reflected in the keyness of felt and impressed.

39) My treatment was very rapid and efficient. Hospital facilities - exemplary. Staff - all efficient, but very compassionate and knowledgeable. I felt safe at the hospital.

(Under 1 year)

Another keyword, thank, is used by patients in this group to express thanks, typically to the staff who have performed the procedure or provided the treatment in question. Again, this reflects the wider tendency within this group to focus on a specific episode of treatment, and small number or single member of staff.

We now move onto the keywords for the comments provided by patients who have received patients for a year or more. These are given in Table 6.

Table 6: Top 30 keywords for the 1 year and over group compared to the under 1 year group.

| are (24,045), years (7,091), is (34,292), have (62,873), myeloma (1,737), has (16,930), always (12,708), been (34,514), secondary (1,100), trial (1,523), unit (7,603), now (5,334), haematology (1,823), since (3,688), transplant (735), am (12,913), pharmacy (1,928), stem (632), ago (1,765), 2013 (563), sometimes (4,135), 2014 (948), last (3,085), oncology (4,895), drugs (1,746), 2012 (431), cell (788), monthly (966), trials (537), drug (890) |

Where the comments from patients in the under 1 year group were characterised by a focus on narratives of events that were linguistically situated in the past, as indicated through a plethora of past-tense verb keywords, the keywords for the 1 year and over feedback suggest a tendency for this group to describe events and circumstances in the present tense (are, is, am). Meanwhile, the keywords have, has and been tend to be used in the present perfect to frame events and circumstances as occurring continuously (‘So far the care has been excellent.’), repeatedly and continuously (‘My medication has been changed at least twice’), or in the recent past and with some relevance or consequence to the present (I feel very privileged to have been cared for by my group of hospitals.). Overall, this creates the
impression that feedback is based not just on a single visit to a provider but, rather, reflects longer-term and even ongoing experiences.

The characteristic use of present perfect in these comments also explains the keyness of temporal keywords, which patients use to describe how long they have been attending a particular provider (years, now, since, ago, 2012, 2013, 2014), the frequency of their visits to the provider (monthly), and to mark out their most recent visit in their feedback (last). These almost autobiographical passages also frequently include mentions of the types of cancers that patients have been diagnosed with (myeloma, secondary). As the feedback form does not ask respondents to provide information about how long they have attended a provider, or about the frequency of their visits, the patients in this group have provided this detail voluntarily. It is thus safe to assume that they deem it relevant to their feedback which, as we have discussed, tends to be based (or at least is linguistically framed as being based) on longer-term experiences of a provider. At the same time, patients could be marking out such information as salient in their comments as a way of representing themselves as knowledgeable and experienced patients who are thus particularly well qualified to evaluate the standards of a provider. Even if this function – of legitimating their feedback (see van Leeuwen 2008) – is not the patients’ intention, it could nevertheless be the effect on those who analyse and monitor such feedback.

Descriptions of experiences of a provider as being long-term, frequent and ongoing also serve as a textual warrant for evaluations of the consistency of care standards, indicated in uses of the temporal adverbs always and sometimes.

40) I have been under treatment at [anon] Hospital for many years, and have always been treated with great care and consideration.

(1 year and over)

41) Less waiting times in out patients clinic, but this can vary each time. Sometimes quick other than times running up to an hour/ one and a half hour late.

(1 year and over)

Another distinction between the under 1 year group and the 1 year and over group indicated in uses of the keywords is the characteristic of the latter to focus feedback on teams and units (unit, haemotology, pharmacy, oncology), and can be contrasted with the focus on individual staff members (particularly surgeons and consultants) that was indexed in uses of the keywords Mr and surgeon for the other group.

Other keywords in this category do not indicate as much about the linguistic and rhetorical strategies that patients use in their feedback but, rather, indicate differences in the types of treatment that members of either group typically receive (transplant, stem, cell, trial, drugs, trials, drug).

5. Conclusions

This study has examined patient feedback on NHS cancer care in England, comparing written comments from patients based upon the length of time from their first treatment. For this, we
grouped the patient feedback into three groups reflecting treatment duration: under 1 year, 1-5 years, and over 5 years. First, we explored the satisfaction rates of each of these groups by comparing what proportion of each gave each of the scores between 0 and 10 in their feedback. Patients in each group gave ratings in approximately the same proportions, with around 86% of patients who provided comments giving scores of at least 8, regardless of the amount of time they have been receiving treatment. While the highest rating of 10 was the most popular score for patients at all treatment stages, those who have received treatment for less than one year were the most enthusiastic, being around 4% more likely to give this highest score than the other patients. This suggests, then, that patient satisfaction rates are very high overall and have remained relatively stable for patients across the duration of their treatment, at least during the period under study (2015-2018).

We then compared the themes of positive and negative feedback for each of these groups, based on qualitative thematic analysis of samples of 100 positive comments and 100 negative comments for each of the three groups. The first thing to note is that the range of themes identified in the samples was relatively narrow, with a large degree of overlap between the groups. This suggests that, overall, the types of themes – and the priorities and concerns that these index – which inform patients’ feedback are relatively similar, regardless of how long those patients have been receiving treatment. We did, however, also note some differences in the prevalence of particular themes across the groups, with these differences highlighting interesting trends relating to treatment duration in particular. Patients in their first year of treatment tend to focus on a single or small number of episodes of treatment. This entails a more pronounced focus on themes such as the effectiveness of a particular procedure, facilities, food, parking and time spent in appointment waiting room and at the pharmacy. On the other hand, feedback from patients in the 1-5 years and over 5 years groups, which exhibited many similarities between them respecting the prevalence of feedback themes, could be characterised as taking a more holistic approach, with the comments reflecting multiple experiences, often over many years, and typically with different staff members, departments and providers. As such, the feedback from these groups tended to focus more than the under 1 year group on aspects such as co-ordination between providers, staff shortages, care being spread out over multiple hospitals, and waits to be given (particularly follow-up) appointments and to receive test results.

It is beneficial for the NHS, and potentially other cancer care providers, to be mindful of such differences, as such insight can help to support to design and delivery of care that matches patients’ priorities as these potentially change as they progress through treatment. Furthermore, it may be useful for providers like the NHS to be aware of the types of themes that are more or less likely to be addressed in feedback given by patients at different stages of treatment, so that providers may focus on feedback from certain groups if they are interested in monitoring particular issues. For example, feedback from patients within the first year of treatment may be more useful for learning about the standard of facilities, while issues around care co-ordination are more likely to be reflected in comments from who have been receiving treatment for longer.

The third part of our analysis took a more linguistic focus, as we used keywords to examine language use that was characteristic of comments written by patients who received treatment for under 1 year relative to patients receiving treatment for 1 year and over, and
vice versa. When analysed in context, keywords in both groups substantiated many of findings from our thematic analysis of the samples of positive and negative feedback, thus providing evidence that such patterns are indeed generalisable beyond the samples we analysed. Yet some of the keywords also provided new insight regarding the ways in which patients linguistically framed their evaluations, particularly in terms of what aspects were foregrounded and the types of rhetorical strategies patients used to bolster their credibility and their claims. Patients in the under 1 year group tended to base their feedback on a single or small number of visits to a provider – typically procedures undertaken at hospitals – which were characteristically formulated as narratives and located in the past. Their feedback was thus relatively precise, and often focussed on the procedures and individuals involved, as well as how they felt at the time and in the period immediately following the treatment. We could interpret this recounting of past events with more characteristic emotional self-disclosure as a type of emotional narrative designed to make more personalised appeals to readers. Such narratives can be viewed as invoking the kind of mythopoetic legitimation described by van Leeuwen (2008); rather than trying to present their experiences as being necessarily representative, then, the tellers of these stories (who were characteristically in the under 1 year group) convey the importance of their praise and complaints in terms of the (emotional) impacts that the attested service experiences had on them personally.

On the other hand, patients in the 1 year and over group made greater use of present-tense verbs and framed their experiences as ongoing, or at least as occurring in the recent past but with results and effects that evident in the present. Rather than focusing on individuals, keywords for these comments indicated a focus on entire teams and departments, which is indicative of a wider focus of evaluation within this feedback, which addresses multiple individuals and departments, often across many years. The feedback from this group also contained more autobiographical information, for example with patients recounting their original diagnosis and providing details about how long they had been visiting a particular provider. We have argued that such information, which is not requested in the free-text box sections of the feedback form, is foregrounded by patients perhaps as a rhetorical strategy to bolster their credibility as experienced patients whose evaluations are based on long-term experiences, and so ultimately legitimate their perspectives and the value of their feedback.

The rhetorical strategies that characterise the written feedback from patients in the under 1 year and 1 year and over groups can therefore be contrasted against each other, with the former relying on emotional appeals based on a single experience and the latter based on presenting the patient’s perspective as being based on long-term experiences and thus being potentially more generalisable. Whichever strategy is likely to be most effective is difficult to predict and may depend on the individual reading and interpreting the feedback. Whatever the case, it is important for the NHS and other feedback monitors to be aware of such rhetorical strategies, as these may create the unhelpful impression (knowingly or otherwise to the patients using them) that some patients’ feedback is more valid than others’.

Taken together, then, the three perspectives we have adopted on the feedback data in this study provide a range of complementary insights into how written feedback given by patients at different points in their treatment may differ, but also in the ways that it is similar too. The thematic analysis in Section 4.2 and the keyword analysis in Section 4.3 gave some overlapping findings, though each also gave unique insights too. The thematic analysis was
useful for understanding content in terms of what drove patients’ evaluations, while the keyword analysis was useful for understanding the form that these evaluations took, and the lexi-co-grammatical characteristics of feedback from the two groups and how these reflected higher-level rhetorical strategies through which feedback was not only given but also legitimated. While keyness was useful for understanding what distinguished the two groups linguistically, a limitation of the approach is that the focus on difference that underlies the keywords procedure forces us as analysts, in turn, to focus on what is different rather than similar about the datasets (in our case, patient groups) under study. However, this shortcoming was, to an extent, buffered by the preceding thematic analysis, which allowed us to see the ways in which the two groups were similar to one another. Rather than being viewed as mutually exclusive, then, the examination of content and form, represented respectively by the aforementioned sections of our analysis, has enabled a triangulated perspective on our feedback data which arguably lends more robustness to the findings of both parts of the analysis.

As discussed at the beginning of this paper, our stakeholder partners within NHS England & NHS Improvement set us a series of questions to answer about this feedback data, all of which oriented to content rather than language. This is understandable, and likely reflects the experience of others collaborating with non-linguist partners. Yet analysis such as that reported in this article, which has developed from the original aims set out by our partners at NHS England & NHS Improvement, demonstrates, we hope, how applied linguists working with non-linguist stakeholders can nevertheless use (corpus) linguistic tools to answer what appear, at least on the surface level, to be non-linguistic questions. Our experiences on this and similar other projects has taught us that a linguistic focus can certainly add value to a focus on content alone, and that the challenge for corpus linguists in particular is in persuading stakeholders of the value of a linguistic focus, as well as of corpus linguistic methods in particular (see also: Brookes and Harvey 2016; Brookes et al. 2017). This is certainly not an insurmountable challenge, and we have found it beneficial to bring stakeholders along with us, and that this helps to ensure that the methods we are using and the findings that these methods are giving us are indeed of value to our stakeholder partners and have not taken us too far away from their priorities. Even questions which do not orient to language on the surface level can, in many cases, be approached through a linguistic lens. We have found this to be an effective way of demonstrating what linguistics, and corpus linguistics, can add, while mitigating the risk that our findings or not relevant or of interest or value to our partners.

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