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Experiences of Care of Patients with Cancer of Unknown Primary (CUP): Analysis of the 2010, 2011-12 & 2013 Cancer Patient Experience Survey (CPES) England: Final Report

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cancer of
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Contents

1. Background and aims

Patients with cancer of unknown primary (CUP) have metastatic malignant disease without an identifiable primary site. CUP is reportedly the fifth most common cause of cancer death in the UK, with 10,625 cases in 2012 (NCIN/CRUK 2015). The National Institute for Clinical Excellence (NICE) published guidelines for the management of CUP patients in 2010, which for the first time developed a taxonomy of definitions that reflected different phases of investigations for CUP (see Appendix 1). The Guidelines also recommended the establishment of a specialist CUP multi-disciplinary team (MDT) in each NHS trust (NICE 2010). However, with the exception of two previous qualitative studies (Boyland & Davis 2008; Richardson et al. 2013), there is virtually no published research on quality of life (QoL), psychosocial aspects of CUP and experience of treatment and care. These two studies indicate patients with CUP experience high levels of diagnostic and therapeutic uncertainty, and are frequently not well supported over their illness trajectory, with poor coordination of their care (Richardson et al. 2013; Boyland & Davis 2008). CUP patients often face delays to treatment as they are moved from one MDT to another in what has been described as ‘MDT tennis’ (Richardson et al. 2013). These conditions arguably create a set of unique issues for CUP patients and their families, in addition to the challenges typically faced by patients with cancer.

In the UK, the NHS Cancer Reform Strategy (DH 2007), Outcomes Strategy for Cancer (DH 2011) and recent Cancer Taskforce (CRUK 2015) documents highlight the important role of patient experiences in measuring and improving clinical quality. The national Cancer Patient Experience Survey (CPES) is an extensive, England-wide programme of research about cancer patients’ experiences of care while undergoing inpatient or day-case treatment. Quality Health, on behalf of NHS England, has now administered the CPES at four observation time-points (2010; 2011-12; 2013; 2014). Quality Health publishes a national report following each survey and provides local data to each English Trust on the responses of patients for whom they are the primary provider of cancer care.

Aims and objectives

This study was commissioned by the CUP Foundation to analyse the content of the free-text responses of CUP patients participating in the CPES in England. Free-text data was analysed for the three observation points for which data was then available (2010; 2011-12, and 2013).
Specific objectives were to:

- Determine issues of concern reported by patients with CUP;
- Identify challenges that patients experience during their illness and treatment pathway; and,
- Describe aspects of care patients with CUP would like to see improved

2. Methodology

Quality Health administered a population-based postal survey at three points of observation: 2010, 2011-12 and 2013. The survey included all adult patients (aged 16 years and over) in England with a diagnosis of cancer, who had been admitted to an NHS hospital as an inpatient or as a day case patient over a three month period.[1] The research team conducted a secondary analysis of data collected during these surveys.

2.1 Cohort identification

All NHS health trusts treating adult patients with cancer in England were included.[2] Patients were identified from data provided by health trusts, selected from local patient administration systems. Patients were identified as CUP using the tenth revision of the International Statistical Classification of Diseases and Related Problems (ICD-10) codes: C77 (Secondary and unspecified malignant neoplasm of lymph nodes), C78 (Secondary malignant neoplasm of respiratory and digestive organs), C79 (Secondary malignant neoplasm of other and unspecified sites), and C80 (Malignant neoplasm, without specification of site) (WHO 2011) (see Appendix 2).

2.2 Questionnaire and design content

Questionnaires included questions on socio-demographics, quality of treatment and care, disease status and Long Term Conditions (LTCs) (QH 2014). Three free-text comment boxes were placed at the end of the questionnaire, after the closed questions, and asked the following questions:

- Was there anything particularly good about your NHS care?
- Was there anything that could be improved?
- Any other comments?

2.3 Survey process

The survey was distributed by post, with two reminders sent out to non-responders only (QH 2014). Covering letters were sent out on hospital trust headed paper and signed by a member of the trust's staff, usually the chief executive (QH 2014). A language leaflet was also enclosed offering translation services and a pre-paid return envelope was included so that patients could respond without financial cost.

The response rates for CUP patients providing comments to the CPES in each year, as a proportion of those returning questionnaires were: 68% (n=3038) in 2010; 66% (n=3149) in 2011-12; and 67% (n=3055) in 2013.

2.4 Ethics approval and data management

NHS England has ownership of CPES data, but Quality Health holds these data. The process for securing approval from NHS England to access the free-text data was finalised on 12/09/14. Approval was given on condition the research team conform to the Information Standards Board (ISB) Anonymisation Standard for the Publication of Health and Social Care Data (ISB 1523 Amd

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[1] The 2010 CPES included patients who received treatment between 1st January – 31st March; The 2011-12 and 2013 surveys included patients who received treatment between 1st September and 30th November.

[2] In 2013 this was 155 NHS Trusts, down from 160 in 2011-12 and 158 in 2010.

20/2010). Data from Quality Health were transferred to the research team on 21/10/14 via a secure file transfer service.

The University of Southampton ethics committee approved the study on 12/11/14 (UoS Ethics ID: 12313).

2.5 Data source and format

The Excel format of data received from Quality Health comprised free-text responses for each case (respondent) in separate columns, according to whether the comment had been entered under response headings for 'good' experiences of care, areas to be 'improved' and any 'other' comments. Responses were anonymised by Quality Health prior to the research team's receipt of data (i.e. by removing names of people, specific places and other details that could be used to identify patients). Free-text comments were extracted from the CPES data set as individual text files and loaded into the NVivo10 qualitative data analysis software package.

2.6 Data analysis

Data were subjected to a thematic content analysis, informed by a three-stage coding process (Mason 2002).

Stage One: *Data sorting into comment categories*

Stage one involved analysis of the semantic content of free-text responses (i.e. whether they contained references to nursing care, surgery, chemotherapy etc. and whether comments in relation to these areas were of a positive or negative nature, either reporting good or bad experiences). A coding framework for sorting free-text data from the CPES had been developed within a previous study of responses to the Welsh CPES 2013 (WCPES) (Bracher et al. 2013). Once the main coding framework had been established (i.e. the framework was able to accommodate the majority of comments without the need for additional categories), a sample of 200 randomly selected comments were double-coded by two researchers (MB, RW). Coding agreement between the two researchers was 80% (Cohen's Kappa). Any conflicts were resolved through discussion between coders.

This existing coding framework was used to categorise comments for this study of CUP CPES data. Search criteria were developed for each category, using terms gleaned both from the knowledge of researchers, and from term-frequency and unique terms analyses of the coded data in each category from the WCPES. This led to the development of a search strategy for each theme (see Appendix 3), which was used to identify relevant comments.

Responses to the free-text question frequently contained comments relating to several categories, so the number of comments does not necessarily match the number of participants. Also, as each new search for comments on particular themes would retrieve a new set of free-text data, it would sometimes be the case that some comments would be retrieved for, and coded under, more than one theme. This was especially the case for comments that described care by more than one type of health care professional, and many comments (particularly positive comments) had a structure typified by the examples given below:

Staff from nurses to consultants have provided a kind personalised service. (Male, 66-75 years, 2010 CPES).

Doctors and nurses, without exception, have been and continue to be fantastic. The whole process runs so smoothly and everyone is so friendly whilst, at the same time, being so professional. (Female, 51-65 years, 2010 CPES).

A degree of double coding of some comments is therefore present within some categories.

Stage Two: *Detailed coding .*

Once all comments had been coded to stage one level, individual categories (codes) were subjected to a second stage of more detailed sorting, in order to explore specific content within different areas of cancer care. For example, at stage one comments relating to nursing care were sorted to the category 'Nursing'. At stage two, comments within this category were sorted into 'NursingPositive' or 'NursingNegative' depending on their character, and then sorted further according to sub-categories within nursing care (i.e. what specifically was 'positive' or 'negative' about the care, for example, patient perceptions of information provided by nurses or the manner in which they were dealt with by staff). Categories derived from stages one and two of coding provide the basis for themes discussed in the main findings section of this report.

Stage three: *Identification of overarching themes from comment categories.*

In addition to themes derived from the semantic content of comment categories, several overarching themes emerged from analysis of similarities in the content between categories. These emergent themes refer to aspects of cancer patient experience within the data that cut across different phases of the cancer journey (e.g. communication issues), and are explored in the discussion section of this report.

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3. Findings

3.1 Overview of findings

In total, 9242 patients with CUP provided comments over the three periods of observation, and consistent numbers at each observation point: 3038 comments in 2010; 3149 comments in 2011-12; and 3055 comments in 2013. Table 1 shows the demographic characteristics of patients with CUP who provided comments, which remained relatively constant across the three surveys. More detailed socio-demographic data are provided in Appendix 4. Men comprised just over a third of patients who responded to the free-text question, with the majority of CUP free-text respondents being within the 51-65 and 66-75 year age groups.

Characteristic	**2010 (n=3038)**		**2011-12 (n=3149)**		**2013 (n=3055)**		**Total**	
	n=	%	n=	%	n=	%	n=	%
Gender								
Men	1119	36.8	1136	36.1	1121	36.7	3376	36.5
Women	1919	63.2	2013	63.9	1934	63.3	5866	63.4
Age groups								
16 – 25 years	8	>1	6	>0	4	>0	18	0.19
26 – 35 years	32	1.0	24	0.7	22	0.7	78	0.8
36 – 50 years	349	11.4	322	10.2	224	7.3	895	9.6
51 – 65 years	1145	37.6	1189	37.7	938	30.7	3272	35.4
66 – 75 years	981	32.2	938	29.7	1108	36.3	3072	32.7
76+ years	523	17.2	514	16.3	759	24.8	1796	19.4

Table 1: Demographic background for CPES respondents with CUP

The length of comments was highly variable ranging from one word to several paragraphs, with a mean length of 64.2 words. Comments provided by female patients tended to be longer than comments provided by male patients (54.2 and 69.9 words respectively). The length of comments from patients with CUP were also longer than those provided by patients who responded to the WCPES (mean 46.8 words) who could have any tumour type, and this held for both men (41.2 words) and women (51.7 words).

Comments were retrieved from the dataset for seventeen categories, which constitute a thematic framework previously developed deductively from free-text responses to the Welsh CPES (2013) (Bracher et al 2014). The seventeen comment categories are organised into four groups: cross-cutting issues; health care professions; treatment specialisms; and other quality of life concerns (see Table 2). For each category explored, Table 2 shows: the number of respondents who provided related comments; the ratio of negative to positive comments; whether there was an overall positive or negative balance of comments; and the percentage of the total number of comments that were coded in them.

Ratios of negative to positive comments varied widely between categories. Of the comment categories explored, positive comments were predominant for eight ('manner of staff communication'; 'consultants'; 'nursing'; 'Clinical Nurse Specialists'; 'chemotherapy'; 'radiotherapy'; 'surgery'; and 'palliative care'). A majority of negative comments were observed within the remaining nine themes ('inter-agency communication'; 'waiting for appointments/ investigations';

Table 2: Framework of comment categories with counts and ratios of positive or negative comments

Comment category	Year	Negative comments (n=)	Positive comments (n=)	Negative to positive ratio (n : 1)	Overall ratio of comments +ve or -ve	CUP dataset coverage (%)
1. Cross cutting issues						
Inter-agency Communication	2010	345	150	2.30	- ve	16.0
	2011-12	344	156	2.20	- ve	14.9
	2013	331	139	2.38	- ve	15.3
Staff communication with patients	2010	73	295	0.24	+ ve	12.1
	2011-12	82	298	0.27	+ ve	12.0
	2013	89	221	0.40	+ ve	10.4
Waiting for appts/ investigations to be arranged	2010	94	61	1.54	- ve	5.1
	2011-12	91	63	1.44	- ve	4.9
	2013	88	72	1.24	- ve	5.2
Waiting time on the day	2010	372	10	37.20	- ve	12.6
	2011-12	352	10	35.20	- ve	11.5
	2013	299	12	24.92	- ve	10.2
Investigations – receiving results	2010	134	27	4.96	- ve	5.0
	2011-12	184	30	6.13	- ve	6.7
	2013	165	37	4.46	- ve	6.32
2. Health care professions						
GPs	2010	210	113	1.86	- ve	10.6
	2011-12	219	110	1.99	- ve	10.4
	2013	220	91	2.41	- ve	10.1
Consultants	2010	39	88	0.44	+ ve	4.2
	2011-12	51	156	0.32	+ ve	6.6
	2013	49	98	0.50	+ ve	4.8
Nursing	2010	340	580	0.58	+ ve	29.5
	2011-12	289	399	0.72	+ ve	21.8
	2013	284	409	0.69	+ ve	22.7
Clinical Nurse Specialists (CNS)	2010	18	49	0.37	+ ve	2.2
	2011-12	31	70	0.44	+ ve	3.2
	2013	28	72	0.39	+ ve	3.3
3. Treatment specialisms						
Accident & Emergency	2010	22	5	4.40	- ve	0.8
	2011-12	22	7	3.14	- ve	0.9
	2013	28	12	2.33	- ve	1.3
Chemotherapy	2010	24	231	0.73	+ ve	13.1
	2011-12	33	265	0.48	+ ve	12.5
	2013	58	282	0.21	+ ve	11.1
Radiotherapy	2010	28	102	0.27	+ ve	4.3
	2011-12	43	100	0.43	+ ve	4.5
	2013	32	81	0.39	+ ve	3.7
Surgery	2010	175	380	0.46	+ ve	18.2
	2011-12	195	430	0.45	+ ve	19.0
	2013	170	350	0.48	+ ve	17.0
Palliative care	2010	4	40	0.10	+ ve	1.4
	2011-12	6	43	0.14	+ ve	1.6
	2013	2	40	0.05	+ ve	1.3
Post-treatment care	2010	35	26	1.35	- ve	2.0
	2011-12	33	22	1.50	- ve	1.7
	2013	38	32	1.19	- ve	2.3
4. Other quality of life concerns						
Emotional, social and psychological needs	2010	46	18	2.56	- ve	2.1
	2011-12	24	23	1.04	- ve	1.5
	2013	39	17	2.29	- ve	1.3
Financial concerns	2010	62	5	12.40	- ve	2.2
	2011-12	82	6	13.67	- ve	2.8
	2013	75	7	10.71	- ve	2.7

‘waiting on the day’; ‘receiving results of investigations’; ‘GPs’; ‘Accident & Emergency’; ‘emotional, social and psychological needs’; ‘financial concerns’; and post-treatment care’. The category with the greatest percentage of coded comments was ‘Nursing’, with a predominance of positive over negative comments for each year the CPES was administered (mean 0.66 : 1). The categories in which the ratio of positive comments were greatest over negative comments were ‘staff communication with patients’ and ‘palliative care’. A majority of patients experienced staff as friendly, approachable and able to provide required levels of information. It is also of note that patients reported positive experiences of most treatment categories (e.g. surgery, chemotherapy, radiotherapy and palliative care).

The category of comments under which comments were overwhelmingly negative was ‘Waiting on the day for appointments’, with an average ratio of 32.4 : 1. These comments were also highly prevalent, accounting for 11.4% of all comments within the dataset. This suggests that waiting for appointments to see clinicians or to have investigations was an overwhelmingly negative experience for CUP patients. ‘Waiting for results of investigations’ was also a negative experience for most patients. Another category with a heavy predominance of negative over positive comments was ‘Financial concerns’, although relatively few comments were coded in this category. Patients were particularly concerned about a lack of advice on financial matters or benefit entitlements, especially if they had caring responsibilities or were self-employed. Of the four categories of health professionals, positive comments were predominant for nurses, consultants/specialist doctors and for clinical nurse specialists (CNSs), but negative comments were consistently predominant for GPs.

A trend existed within all themes that positive comments tended to be of a more general quality and scope than negative comments. Essentially, if patients were reporting a negative experience they provided more detail. All counts relating to comments in this report refer to numbers of actual comments provided on any specific theme, and as such negative and positive comments in a given category or theme may not equal the total number of respondents (i.e. because individual respondents may have given both negative and positive comments). There are limitations to counts when interpreting the data without recourse to the content of the comments, as counts do not take into account the strength of comments or their seriousness. It is also important to keep in mind that the data discussed reflect patient perceptions and reflections, and no claims are made by the authors of this report regarding the events described beyond reporting these findings as such.
The next section provides an overview of issues involved for many patients with CUP as they try to understand their condition. Subsequent sections follow the comment categories listed above, with extracts from participant responses used to illustrate sub-themes emerging from the data.

3.2 Issues with CUP

Very few patients (n=10) described their condition as ‘cancer of unknown primary’ or ‘CUP’. Patients frequently described having been diagnosed with ‘secondaries’, ‘secondary cancer’, ‘metastatic cancer’ or ‘rare’ cancers. Other patients appeared to be uncertain or confused with regards the type of cancer they had.

> *My cancer was found by the diagnostic test that is sent out to you at 60 yrs. I was told by the doctor who did the colonoscopy that I had cancer and saw it on the screen and I was not allowed to leave hospital until I had seen a bowel specialist. After the operation I never met the surgeon who operated on me before or after the operation and was passed back to the brain team because the brain cancer was deemed as a secondary cancer. I felt insecure all the time I was in the hospital*. (Female, 51-65 years, 2010 CPES).
>
> *Knowing a bit more about cancer now than I did. I still feel generally ignorant about symptoms, whereas where heart and stroke symptoms seem more understood, both by me and the general public. Very few of my friends know what having secondary cancer means. Also the terms for this seem vague. Is it advanced, metastatic or secondary? All these have been used at times*. (Female, 66-75 years, 2011 CPES).
>
> *My primary cancer has never been 100% proven, making things a bit ‘up in the air’*. (Male, 51-65 years, 2011 CPES).

Some patients who were aware that no primary had been identified nevertheless found it difficult to understand why this should still be the case following several investigations. Not knowing the location of the primary could be very distressing.

> *I first made an appointment with a GP at my surgery re: stomach, feeling full after only a few mouthfuls of food and discomfort in my abdomen. I was told all was well and to return in a month if symptoms continued. I was taken to hospital within a week due to the symptoms. One scan led to another and cancer was found. After a laparoscopy ovarian cancer was found to be the problem. The result of a biopsy revealed it couldn’t be ovarian. No primary was ever found. I am amazed that after having CT, ultrasound, MRI and other scans the true problem was not discovered*. (Female, 51-65 years, 2010 CPES).
>
> *Further detailed information of my cancer needed. Exactly where secondaries are and what kind of problems they could cause. Not knowing can be most distressing as you try to second guess things too much*. (Female, 66-75 years, 2013 CPES).
>
> *I had 2 liver biopsies (the first one did not have sufficient to discern whether benign or malignant). I had a scan whilst in hospital, also a CT scan and an MRI scan. On my discharge, I later received an appointment for an endoscopy when 2 small nodules were discovered in the gullet, a biopsy was taken – they were benign, the tumour on the liver is a secondary and they still do not know where the primary is*. (Female, 51-65 years, 2013 CPES).

Patients indicated that the process of identifying the site of the primary could take some time, meaning delays to the commencement of treatment.

> *The only thing that could be improved was because it was a process of elimination I went from chest specialist, to organ oncologist and after my scans and biopsies finally back to my breast oncologist of 11 years ago. So my treatment didn't' start until end of March – 6 months later*. (Female, 51-65 years, 2010 CPES).

Some patients reported that while they had been content with the level of information with which they were provided when they had originally been diagnosed with a primary, when informed it had metastasised they felt they had received much less information.

> *Superb information concerning breast cancer (type sign nodes etc). When it metastasised to my bones and liver there was no information like para 1. It was just "the cancer has spread" this terrified me*. (Female, 51-65 years, 2010 CPES).

Occasionally there were reported disagreements between clinicians as to the origin of the cancer and the most appropriate treatment.

> *The surgeon at [Hospital 1] was brilliant. The [Hospital 2] told me my tumours were 'inoperable' and yet the surgeon at [Hospital 1] was able to remove them. He is the first person who has been able to give me information and hypothesise on the cause of my cancer. I have a lot of confidence in him*. (Female, 66-75 years, 2010 CPES).

Overall, however, most patients in this sample appeared to believe they knew the primary origin of their cancer.

3.3 Inter-agency communication

In total, 1465 comments (15.8%) described experiences of communication between health care agencies across the three periods of observation (Table 3). These included communication between primary and secondary sectors, between Trust and hospitals, and between departments, clinical teams and health professionals within hospitals. Findings indicate a much higher proportion of negative comments compared with positive comments (i.e. an overall ratio of 2.29 : 1), which remained consistent across the three observation oints. The overall ratio of negative to positive comments was lower for patients with CUP than for respondents to the WCPES (i.e. 2.29 : 1 vs. 3.75 : 1).

Year	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	345	150	495	2.30	16.0
2011-12	344	156	500	2.20	14.9
2013	331	139	470	2.38	15.3
Total	1020	445	1465	2.29	15.8

Table 3 - Breakdown of comments on inter-agency communication by period of observation

Patients reported protracted periods of time for their medical notes and results from investigations to be passed from one hospital or department to the next, and patients were sometimes provided with confused information.

> *Communication between different departments (surgical, cardiac, oncology) is slow and inefficient. It can take 2 weeks for information to cross a corridor to the other department because of bureaucracy*. (Male, 51-65 years, 2011 CPES).
>
> *The contact between health professionals of different trusts, although under the same trust, was quite often 'a shambles', with information not accessible to all parties.* (Male, 51-65 years, 2011 CPES).
>
> *I would be grateful if possible to have all my notes regarding my cancer since I was diagnosed end of [date removed]. I was treated for lung cancer for two years and then told that I did not have lung cancer, however I am told that I have breast cancer. Needless to say I'm puzzled*. (Female, 51-65 years, 2013 CPES).

Notes were often reportedly missing when they were needed at consultations or were apparently lost altogether. Missing or lost notes could potentially lead to treatment delays and required patients to spend part of their consultation times explaining their condition and treatment thus far.

> *Some notes missing, apparently due to new computer programme. However, not acceptable. Quite appalling really, especially when consultant had to ask me for information about my last visit with him*. (Male, 51-65 years, 2010 CPES).

> *Rarely over a series of appointments were my medical records available for the doctor. The most disturbing aspect of this was that doctors had to rely on what I told them and what I could remember of my medical diagnosis*. (Female, 66-75 years, 2010 CPES).
>
> *My bloods are regularly lost and scan results take weeks to get to the oncologist*. (Male, 51-65 years, 2013 CPES).
>
> *It was four weeks after I was admitted but the records from my stay in EAU had not been married with my main records. This has the potential to be dangerous*. (Female, 36-50 years, 2013 CPES).

Some patients experienced continued communication issues between hospital units and personnel that led to confusion and repeated delays and required patients to be continually vigilant and proactive in monitoring their own care. Many of these comments incorporate several treatment types and different types of health professional and so cannot be easily categorised under the discrete themes.

> *Please consider seriously the following events that occurred. Initially attended A&E with suspected renal stone, discharged, no follow-up. GP organised scan at GP surgery as hospital said they would do one but did not. US scan showed abnormality in testicles and enlarged para-aortic lymph node. 1st hospital apt told it was very unlikely to be anything. Did CT scan. Next apt told by registrar it was cancer – surgery/chemo/radiotherapy treatment – on my own for this. next appointment with consultant and took the wife – consultant had no notes – referred to a letter re: renal stone, we told him what registrar had said – 1 hour wait for notes. Consultant – very noncommittal ordered blood tests. Follow up appointment planned for 2 weeks only, came when chased. Then surgery – this took from [date removed] to [date removed]. No follow up apt. told referred to [hospital 1 name removed] – in meantime wound infection. No referral received from [hospital 1 name removed]. Apt at [hospital 2 name removed] – told not malignant – unsure about lymph node therefore biopsy needed. Told this would be in 2 weeks. Apt did not come. Followed it up. Notes on secretary's desk. One more week no response. Secretary said the person who could biopsy was on holiday*. (Male, 66-75 years, 2011 CPES).

Such catalogues of delays could ultimately lead to very poor outcomes for patients in terms of their treatment options and survival.

> *I now know the difference between a good hospital and a bad and it starts at the top. Bad consultants!! Leads to bad nursing practices and bad communication between staff leads to misunderstandings. The worst thing was being overlooked!! Entered hospital as a frightened patient who felt unwell and didn't know what was wrong with me. I left hospital because of an infection still needing a biopsy – which was scheduled for the same day being told it would be dealt with as an outpatient. That referral never happened. I had to chase up that appointment. The consultant's secretary found my notes still in the ward I had been admitted to, no referral had been asked for. That wasted 6 weeks. Then when I finally met the consultant, after examination, told me 'nothing sinister is going on', so consequently no urgent scans took place. I finally found out I had terminal cancer by a consultant visiting me*

> *in hospital after I was admitted with neutropenia following chemotherapy. He came to see me with no notes to explain about neutropenia and went on to tell me my cancer had spread to my bones with no notes to tell me which bones. He guessed my spine, scull, pelvis and chest, then left me. I now have less than a year to live. I'm 55!!!* (Female, 51-65 years, 2010 CPES).

Overall, therefore, the experience of interagency communication were quite negative for this patient group.

3.4 Communication between staff and patients

In total, 1058 comments (11.4%) described experiences of communication between staff, patients and their families (Table 4). These included both the manner of communication of staff in their interactions with patients (e.g. whether they conveyed respect and consideration) and in the information provided (e.g. about both their condition or what to expect from treatment side-effects). Across all periods of observation, the ratio of negative to positive comments was lower for patients with CUP in the English CPES than for respondents to the WCPES (i.e. 0.29 : 1 vs. 1.0 : 1).

Year	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	73	295	368	0.24	12.1
2011-12	82	298	380	0.27	12.0
2013	89	221	310	0.40	10.4
Total	244	814	1058	0.29	11.4

Table 4 - Breakdown of comments on staff communication with patients by period of observation

Communication between health care professionals and patients and their families comprised a number of different issues. It was evident that participants valued being treated as ‘a person’ and as ‘a human being’, by which they meant being treated with respect and consideration. Consideration could be shown, for example, by putting patients at their ease, inviting questions and ensuring explanations were easily understood.

> *I feel like a person, not an illness and was given the correct level of information. I don’t want to know too little but fear being told more than I am able to deal with*. (Female, 66-75 years, 2010 CPES).
>
> *My cancer doctors have given me lots of time in my appointments and answered all my questions thoroughly*. (Female, 51-65 years, 2011-12 CPES).
>
> *Any questions I have are answered clearly and not full of terminology I would not understand*. (Male, 66-75 years, 2013 CPES).

Patients did not always understand the terminology that staff used to describe their conditions, sometimes believed they were not being provided with all the information necessary to make an informed decision about treatment, and could receive conflicting information from different clinicians.

> *I had a young doctor tell me I had three ‘hot spots’ in my bones. I had no idea what she was talking about*. (Male, 51-65 years, 2010 CPES).
>
> *I had 2 major operations on this ward. Not such good experience on the liver unit when I had a liver operation. Lots and lots of mixed messages from the various specialities from different individuals*. (Female, 51-65 years, 2010 CPES).
>
> *Overall you tend to feel that not every option is offered. Some treatments tend not to be mentioned unless you bring them up or see several different doctors. There also seems to be*

> *different opinions on benefits of treatments depending on whether it is a surgical or chemo team*. (Female, 66-75 years, 2010 CPES).

Following treatment, patients sometimes reported they had not received adequate information and preparation for the side effects of that treatment or how to manage them.

> *I would have appreciated a lot more information about my condition and the effects of the treatment from them*. (Female, 51-65 years, 2010 CPES).
>
> *Upon my diagnosis, I was not informed about the effects of surgery and cancer drugs on my fertility. As a result, I only had a very limited chance to store sperm, possibly as a result of surgery also. This one chance had a low count. If I had known all of this sooner, I would have taken steps to store before surgery*. (Male, 36-50 years, 2013 CPES).

There were also reports of a lack of information provided on the care patients were to receive in the post-treatment phase, and difficulty accessing results of investigations.

> *Subsequent to the last surgery I felt there could have been more information/ instruction on post-op care, in particular: treatment of scar tissue; checking of lymph glands; monitoring for other melanoma*. (Female, 51-65 years, 2010 CPES).
>
> *When trying to find out any results the contact with staff was difficult and did not get back to us when they promised to*. (Male, 51-65 years, 2010 CPES).

There could also be a lack of information provided with regards how patients might claim benefits.

> *Didn't find out until 1 and half years after diagnosis that on benefits I could have claimed fuel back and lost nearly £400 before finding out. People need to be actively encouraged to seek financial help out there, as like me they won't ask*. (Female, 36-50 years, 2011-12 CPES).

There were also occasions when patients felt they had been provided with a lot of information in a short period of time.

> *I feel that during consultations you are given too much verbal information which is too much to take in at once. Information should be given over a few appointments and not all in one go*. (Female, 51-65 years, 2010 CPES).
>
> *On the follow up after the first operation perhaps too much information was given regarding the possible, but not probable, spread of the cancer to internal organs where there would be no treatment and life expectancy of 6 months. This was very distressing to my mother who is 89 and she became very upset about something which may happen in the future*. (Female, 51-65 years, 2013 CPES).

The way in which the diagnosis was conveyed was sometimes insensitive and lacking respect and compassion.

> *It was basically 'Yes, you've got bone cancer, it's in a couple of places, go home and have a nice Christmas'*. (Female, 51-65 years, 2010 CPES).

> *I was told by a consultant in the ward I had a month to live. No privacy. Ladies in the ward heard everything I was told and were shocked*. (Female, 66-75 years, 2010 CPES).
>
> *My initial diagnosis consultation was very poor. I was told 'you have cancer' followed by 'you have up to 6 months'*. (Male, 66-75 years, 2011-12 CPES).
>
> *The way I was told I had cancer at the hospital was appalling. Very disrespectful and belittling*. (Female, 51-65 years, 2011-12 CPES).
>
> *When told you have cancer, or in my case terminal cancer, didn't like being told in side room where I had to walk out through the waiting area. Thought I wasn't given even enough time to compose myself after I was told. Think you need more time and privacy after being told*. (Female, 51-65 years, 2013 CPES).

Patients sometimes reported several aspects of poor communication in both the manner of staff interaction and the information they received.

> *Poor communication when diagnosed – insensitive, no hope of treatment, no information regarding assistance, support or benefits. Inconsistent approach from cancer doctors when discussing results from same test*. (Female, 51-65 years, 2013 CPES).

Communication between staff and patients could also be compromised by poor English language skills. With many health professionals from overseas working in the NHS there was scope for such misunderstandings to occur.

> *There have been a few staff I have met where communication is an issue as English is obviously not their first language which can create problems*. (Female, 66-75 years, 2013 CPES).

Overall, however, experiences of communication between staff and patients were quite positive amongst this patient group.

3.5 Waiting for appointments

In total, 469 (5.1%) comments described waiting for appointments to be arranged across the three periods of observation (Table 5). Findings indicated a higher proportion of negative comments over positive comments, which remained broadly similar over the three observation points. Comparing findings with those of the WCPES, a similar ratio of negative to positive comments were identified in both studies (1.35 : 1 and 1.39 : 1 respectively).

Year	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	94	61	155	1.54	5.1
2011-12	91	63	154	1.44	4.9
2013	88	72	160	1.22	5.2
Total	273	196	469	1.39	5.1

Table 5 - Breakdown of comments on waiting for appointments by period of observation.

Comments relating positive experiences of appointments being arranged in a timely way tended to be shorter than negative comments, but conveyed this often as part of a more general expression of satisfaction with the cancer journey.

> *I was impressed with the speed at which I was seen and treated. All staff - nurses, doctors, consultants were excellent*. (Male, 51-65 years, 2010 CPES).
>
> *Everyone was friendly helpful and tried to be supportive and well informed. I received timely appointments*. (Male, 66-75 years, 2010 CPES).
>
> *I had breast cancer operation early [date removed], plus radiotherapy. [date removed] went to GP with back pain, sent for x-ray, before x-ray, had annual appointment with my oncology doctor, told her about x-ray, she arranged scans etc. within weeks. Secondary cancer in my spine. Have received excellent treatment at [Hospital name removed]*. (Female, 51-65 years, 2011-12 CPES).

Patient comments reporting long waits for investigations and treatment to be arranged indicated that these delays greatly impacted upon their sense of well-being. Patients were concerned that their cancer would become worse while they were waiting needlessly and may reduce their treatment options and even prognosis.

> *The problems occur on admin and follow up. My first cancer operation was in 2007. After receiving chemotherapy and reversal of stoma I was told to expect a colonoscopy within 12 months. This did not happen and I chased it although the manual notes were clear the input onto computer was incorrect - I would not have had the test and my further cancer may not have been picked up. Again since my last operation I was told I'd receive a test 3-6 months again this did not happen and I have chased it, a test is due in September but to date an appointment has not been received*. (Male, 51-65 years, 2010 CPES).

> *Waiting so long for your results and treatment is very, very worrying, especially when you are waiting for your chemotherapy and feeling so ill. Nobody should have to wait more than 5 days for the results for anything*. (Female, 51-65 years, 2011-12 CPES).
>
> *I was lost in the system for 54 days with no appointments having been made despite our call to the consultant`s secretary, one call and a reminder e-mail to the hospital. No treatment from [date removed] to [date removed]. No explanation received*. (Female, 66-75 years, 2011-12 CPES).

Overall, therefore, experiences of waiting for appointments were generally negative for this patient group.

3.6 Waiting time on the day

In total, 1055 (11.4%) comments described experiences of waiting on the day for clinic appointments (Table 6). Findings indicated an overwhelming proportion of negative comments over positive comments, which remained broadly similar over the three observation points. Comparing findings with those of the WCPES, a much larger proportion of patients with CUP reported long waiting for appointments (11.4% and 4% respectively), with a much greater ratio of negative to positive comments (4.90 : 1 vs. 31.96). This finding may reflect the higher treatment burden of this group of patients, who may consequently have a greater number of appointments to attend.

Year	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	372	10	382	37.20	12.6
2011-12	352	10	362	35.20	11.5
2013	299	12	311	24.92	10.2
Total	1023	32	1055	31.96	11.4

Table 6 - Breakdown of comments on waiting on the day by period of observation.

A few patients reported waiting times that were not protracted.

> *I have never had to wait or delay treatments and I feel that in my experiences I have been treated promptly and with amazing efficiency at all times and at all the hospitals I have attended*. (Female, 51-65 years, 2011-12 CPES).
>
> *I have been very impressed with every aspect of my hospital NHS care. I never have to wait long in clinic and never feel rushed when in with the doctor or Macmillan nurse*. (Female, 51-65 years, 2013 CPES).

Waiting on the day for appointments was extremely stressful for some patients and not knowing how long the wait would be exacerbates this stress. There were also practical considerations for patients, such as work and family commitments and the need for car parking payments to be ‘topped’ up while still waiting for late appointments.

> *Waiting times for your appointment could be more sensitively handled. The thoughts that run through your mind when awaiting results to cancer are unbearable. For your appointment to then run 25-60 minutes late is not nice*. (Female, 51-65 years, 2010 CPES).
>
> *My last clinic appointment was while my consultant was on holiday and I saw his registrar. The appointment was over 1 hour late and she had not read my notes. I didn’t feel she listened to me*. (Female, 51-65 years, 2010 CPES).
>
> *I could have had my chemotherapy at Guildford earlier instead of July. It seemed a long wait. I felt quite alone at the beginning and would have liked someone to show me where to go and what was expected of me. I am a positive lady but no consideration for my age was given. Often had long waits for treatment. Once sent to wrong chemo department 3 hours before I had treatment. Another time, a two hour wait as my notes and chemo not sent up to ward for treatment*. (Female, 51-65 years, 2011-12 CPES).

> *Sometimes a long wait for follow up appointments and not knowing how long the wait might be especially having parking difficulties and maybe a fine at the end of the appointment*. (Female, 51-65 years, 2011-12 CPES).

Some patients suggested that if they were kept informed of the length of delays, this might reduce the stress.

> *The reception staff could be more communicative explaining delays. Every chemotherapy treatment started late, and almost every consultant appointment*. (Female, 51-65 years, 2010 CPES).

A few patients also recognised that at least some of the delay was caused by consultants ensuring patients have sufficient time to discuss their condition and treatment.

> *The waiting times at the OPD are very long. Nobody complains as we all understand that when we are seen by a doctor, we will in turn have as long as we need*. (Female, 51-65 years, 2011-12 CPES).

Overall, experiences of waiting on the day of appointments were overwhelmingly a negative for patients with CUP.

3.7 Investigations

3.7.1 Overview

In total, 558 (6.0%) comments described experiences of investigations (Table 7). Findings indicate a far higher proportion of negative comments compared with positive responses (5.14 : 1), with the ratio of negative-to-positive comments remaining broadly stable across all three periods. Comparing these findings with those of WCPES, the ratio of negative to positive comments was comparable (12.16 : 1 vs. 11.7 : 1), while a lower percentage of patients with CUP gave comments about chemotherapy compared with WCPES respondents (6.0% vs. 10%).

Year	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	134	27	153	4.96	5.0
2011-12	184	30	212	6.13	6.7
2013	165	37	193	4.46	6.0
Total	483	94	558	5.14	6.0

Table 7 - Breakdown of comments on experiences with investigations by period of observation.

Other comments in this category related to inter-agency communication, communication between health care staff and patients, the speed of investigations, and waiting for the results of investigations (table 8).

3.7.2 Speed of investigations

Across all three periods of observation, a sub-set of patients gave comments relating to speed of investigative and diagnostic procedures following GP referral or Accident & Emergency (A&E) admission, most of which were negative. The majority of comments in this section were general (e.g. ‘Diagnosis too slow’ / ‘my diagnosis was very quick’) or miscellaneous, while for others *speed of initial investigations* and *mis/missed diagnosis* were important issues. In terms of negative comments, examples included the following.

> *I was misdiagnosed when breast cancer spread to my bones. I was told my neck problem was arthritic degeneration. Paid to consult an orthopeadic consultant. Paid for MRI scan. Paid for neck fixing. NHS let me down*. (Female, aged 66-75 years, 2010 CPES)
>
> *It took 11 months before it was confirmed I had cancer. I am appalled about this. It began as a blockage in the urethra. They said it was a kidney stone but couldn't find it. After 3 stents in the urethra a different doctor saw me and booked me in immediately and I was operated on the following day. I have since learnt that a scan in June showed enlarged lymph glands and yet, still nothing was done until the following March. I even asked the said doctor to cut me open and take whatever it was out. I spent almost 1 year worrying that it may be cancer only to discover it was. I don't think anyone should have to wait this long and suffer the mental anguish*. (Female, aged 51-65 years, 2010 CPES)

Year	Category description	Sub-category description	Negative comments (n)	Positive comments (n)	Total comments (n)
2010	Communication between staff/agencies	.	23	.	23
	Communication between patients and staff	.	16	6	22
	Follow-up investigations	.	15	4	19
	Speed of Investigations	(General or miscellaneous)	13	15	28
		Speed of initial investigations	10	.	10
		Mis/missed diagnosis	20	.	20
	MRI scanning	.	6	.	6
	Waiting for results of investigations	.	31	2	33
	Column totals (2010)	.	134	27	**153**
2011-12	Communication between staff/agencies		28	.	28
	Communication between patients and providers		24	5	29
	Follow-up investigations		29	5	34
	Speed of Investigations	(General or miscellaneous)	38	13	51
		Speed of initial investigations	7	.	7
		Mis/missed diagnosis	8	.	8
	MRI scanning		16	6	22
	Waiting for results of investigations		34	1	35
	Column totals (2011-12)		184	30	**212**
2013	Communication between staff/agencies		15	2	17
	Communication between patients and providers		36	6	42
	Follow-up investigations		13	1	14
	Speed of Investigations	(General or miscellaneous)	37	18	55
		Speed of initial investigations	3	.	3
		Mis/missed diagnosis	20	.	20
	MRI scanning		6	8	14
	Waiting for results of investigations		35	2	37
	Column totals (2013)		165	37	**193**
Total	.	.	483	94	**558**

Table 8 - Subcategories of comments on investigations by period of observation.

> *Despite my previous cancer history and the symptoms I presented, after numerous visits to his surgery my GP referred me to a colorectal surgeon. After unnecessary tests the colorectal surgeon eventually arranged for a bone scan on [date removed] and the follow up appointment to obtain the results was for [date removed] - a wait of 10 weeks. It was not until nearly a year from my first GP appointment when a different GP at the same surgery intervened, that I was given an appointment with an oncology consultant*. (Female, aged 51-65 years, 2011-12 CPES)
>
> *After seeing my GP who referred me to hospital because of high iron levels, I waited a long time to get an appointment and it was then that, when I finally got an appointment, which was a cancellation by a patient that I went to the haematology clinic. It was then, after they scheduled a scan, that I was diagnosed. I felt it was a long time before I could get an appointment even though my doctor ordered a liver and abdominal scan, which I had very quickly and it was then that they found a suspicious spot on my liver. Once I had seen the doctor at the haematology clinic, things progressed quite quickly*. (Female, aged 66-75 years, 2011-12 CPES)
>
> *I was rushed to [name removed] Hospital, with internal bleeding, bad stomach pains, and had been very weak and ill for months. I had lost 3 stone in weight in 2 months. I was told by a junior doctor that I would have 5 or 6 "tests" next morning. At 10am next day a senior doctor (a Dr [name removed]) crossed off all the tests and told me they had stopped the bleed and I was being discharged, after I protested about this and asked why, he told me they did not have the facilities to do the tests (which was a lie). 2 months later having lost another stone, and was vomiting blood as well as passing it, in worse pain, I was taken to MRI on the Monday and by the Friday I had had a tumour removed (and half my stomach) but it had by now spread to lymph nodes and my liver*. (Male, aged 51-65 years, 2013 CPES)
>
> *My cancer was not diagnosed until after my third admission to [hospital name removed]. Each admission was for the same problem, and they continued to treat me for a neck abscess instead of looking for another cause. CT scan only provided on 3rd admission*. (Male, aged 36-50 years, 2013 CPES)

Where delays in diagnosis did occur, and/or where these involved misdiagnoses, delays to treatment were often lengthy, with many patients linking this to poor prognosis. In terms of positive comments, the following were examples of what tended to be more general or miscellaneous responses.

> *I was satisfied that [hospital name removed] speedily performed the biopsy*. (Male, aged 66-75 years, 2010 CPES)
>
> *On first seeing the cancer specialist, a physical examination and question and answer session suggested I had prostate cancer so treatment was started immediately. A biopsy was carried out within a week and a bone scan within two weeks*. (Male, aged 66-75, 2011-12 CPES)
>
> *Accident and emergency at the [hospital name removed] was excellent, they took my symptoms seriously and diagnosed the advanced cancer within 24 hours*. (Female, aged 36-50 years, 2013 CPES)

Positive comments tended to appear in the wider context of comments that described a general speediness throughout the cancer journey, often with attendant expressions of confidence in the treatment and beliefs in increased likelihood of a positive outcome.

3.7.3 Waiting for the results of investigations

A number of patients commented on the length of time that they had spent waiting for the results of investigations, almost all of which were negative.

> *Yes I had to wait 8 weeks for the result of my CT scan which caused me to get worse*. (Male, aged 66-75 years, 2010 CPES)
>
> *Initial diagnosis was very long because I was first referred to (unreadable) - this at department and I eventually saw an endocrinologist who recognised symptoms and CT scan. I felt it took a long time to be transferred*. (Female, aged 66-75 years, 2010 CPES)
>
> *Reporting and discussion sooner after assessments e.g. CT scan / blood tests. Long waiting time for results of diagnostic procedures, even 2 weeks is stressful when waiting*. (Male, aged 66-75 years, 2011-12 CPES)
>
> *I had to wait too long for results of a biopsy - was told would have appointment in 5-6 weeks but it was 3 months and then that was cancelled indefinitely. After many phone calls, I eventually spoke with a registrar a month later, and was given the results*. (Female, aged 66-75 years, 2013 CPES)
>
> *Results for CT scans at [name removed] Hospital are never written up in time for one's appointment. I have had one appointment, 2 weeks, 3 weeks and 4 weeks after CT scan, where results are not available. This is not good enough*. (Female, aged 36-50 years, 2013 CPES)

Delays in receiving the results of investigations were often attributed to issues with poor inter/intra-agency communication. In addition, the experience of any delay was associated strongly with increased stress and expressions of anxiety.

3.7.4 Communication relating to investigations and diagnostic services.

A number of patients provided comments about communication relating specifically to diagnostic services. These related to two main areas; *communication between patients and staff/agencies* and *communication between/within agencies*. In both cases the vast majority of comments were negative.

Communication between patients and staff/agencies

Negative comments in this area generally referred to the accuracy or timeliness of information on the results of investigations, and/or the manner in which these were relayed to the patient.

> *I was treated for 2 years for the symptoms that turned out to be cancer. I had several diagnostic tests but these did not show any illness. The specialist doctor I had been seeing therefore presumed I had IBS but I was told this by letter & was not given the opportunity to tell the doctor my symptoms had become worse. When I was finally diagnosed with cancer 6 months later, the information I was given on my initial consultation proved to be totally incorrect & the doctor who told me I had cancer was totally the wrong person to deliver this news. After my initial diagnosis I was sent for test after test without seeing a doctor who was in charge of my case. I had no idea what was going on, and I felt the doctors in charge of my case didn't either. I was given very little support & felt totally alone. The care & treatment I received at the start of my cancer was totally inadequate and it was not until I was admitted to hospital that my treatment improved through contact with your palliative care team, who*

> *are exceptionally good! If only I'd been given a scan earlier! (Female, aged 36-50, 2010 CPES)*
>
> *I was told I had two tumours, and had to go for liver biopsy, which showed tumour was cancerous. I was under the impression that both tumours were on my liver, this was in February. 15 weeks later I found out that one was on my liver and one on my lung, which nobody had mentioned to me. I also received a letter to go and see the oncologist the day before I got my liver biopsy results, so I knew before I saw the consultant that I had liver cancer. I think the insensitivity of both of these incidents was appalling*. (Female, aged 51-65 years, 2010 CPES)
>
> *They will not give me a scan or give me any more information on where else it is spread. I would like to know how long roughly I have left seeing as I am only [age removed]. Why won`t anyone let us see how far it is spreading, and have a scan to show us without all the [obscenity removed].* (Female, aged 36-50 years, 2011-12 CPES)
>
> *Continuity of care (5 different consultants). Honesty of doctors. Discussing of options. The way you are told its terminal `The scan didn`t show what we wanted` - previous time this meant we need a clearer/different scan but this time they meant cancer out of control*. (Female, aged 36-50 years, 2011-12 CPES)
>
> *Consistency of the doctor seen as they know your history and new doctor obviously haven't read the files as they get a lot wrong. Honesty about scan results. Full picture. Have had instances where the written scan results are different from what the doctor said*. (Female, aged 36-50 years, 2013 CPES)
>
> *Being given the opportunity to see a scan (or bits of it) this was shared initially but now there are no computers in examination rooms: Information about "what to expect" from the CT Scan department. I arrived for my first one and had no idea I had to drink "fluid" no idea what was in it, no idea there would be an intravenous cannula (which took 4 attempts to set up) it was upsetting - the only service to upset me. I have had lots now and know what to expect and all have gone well - better support for first timers*. (Female, aged 51-65 years, 2013 CPES)

The comments in this section cover a range of concerns; however, most speak to a desire for timely and accurate information provision, and for this to be delivered in a sensitive and caring manner.

Though fewer in number, positive comments in this area provide a direct contrast to negative experiences of communication between staff and patients.

> *I had many opportunities to discuss with the surgical consultant as different scans/biopsy results came through, prior to me having surgery. He arranged a biopsy on my back to give me a clearer diagnosis and phone me directly at home to tell me that this could go ahead. After having lymph nodes removed in groin, I was seen immediately by registrar in [hospital name removed] when I was uncertain about fluid collection, this was after I had gone home. The district nurses in [name removed] were brilliant. They came every day for about a month do dressings. Very supportive*. (Female, aged 51-65 years, 2010 CPES)
>
> *The efficiency, care and compassion of the staff of the bone scan unit at [hospital name removed] was exemplary. They met appointment times, explained procedures and gave me confidence and comfort*. (Female, aged 66-75 years, 2011-12 CPES)

> *My doctors have been very straight with me e.g. sharing scan results by showing me on the computer screen, and being clear about pros and cons of treatment options and I appreciate that*. (Female, aged 66-75 years, 2013 CPES)

In these comments, there is a contrast in experience relating to the timeliness and manner in which diagnostic information was provided to patients. Specifically, availability of specialist staff to answer questions, and understanding of the treatment options available, were factors associated with more positive experiences in this stage of the cancer journey.

Communication between and within agencies relating to investigative and diagnostic procedures
Patients providing comments in this area (of which almost all were negative) tended to focus on poor inter/intra-agency information sharing, and attendant delays or issues in treatment resulting therefrom.

> *The main failure was the fact that on more than one occasion the wrong medical notes were produced. (There of a patient with the same name and similar number). This could have caused the wrong treatment being given, as on one occasion due to the incorrect notes being consulted I was told that I was HER2 negative, where as I am in fact HER2 positive. As a result of this whenever I had blood tests or scans there would be doubt in my mind as to whether the correct result would go onto my notes or the other patients. This has caused much stress and concern throughout my treatment. P.S. on one occasion I was told I had thyroid cancer when I hadn't*. (Female, aged 66-75 years, 2010 CPES)

> *Administration / communication between staff absolutely appalling in terms of getting a diagnosis. Hence it took over 6 months to identify the re-occurrence of an existing cancer. I.e. from routine 6 monthly mammogram to confirmation that the cancer had returned in the same place again. December 01 - July 08. Muddles, cock ups, minutes of reviews missed. Correction of phone number etc. in the department doesn't seem to mean that your details are changed in other departments hence doctors ringing out of date numbers that you have changed at least once*. (Female, aged 51-65 years, 2010 CPES)

> *The treatment received from each centre of expertise is excellent. However, the communication between these groups seems to be poor. For example, it took 5 weeks to send a copy of a CT scan from [hospital name removed] to the [name removed] Hospital and it is bizarre that it is the patient that has to tell the consultant the date of a CT scan so that a clinic can be arranged to discuss the results*. (Male, aged 66-75 years, 2011-12 CPES)

> *I think questions 69 is the key one. In my experience no real patient understanding, just different specialists [surgeon, x-rays, experimental] with no real understanding for each other's work. To have a major operation and then to be told straight after that the melanoma has spread elsewhere is not good news and it was delivered badly/bluntly by the x-ray consultant. Process now: Delays in getting monthly pills, co-ordination scans, any improvements in check-up, pills issue and CT scans [and feedback] would be welcome*. (Male, aged 36-50 years, 2011-12 CPES)

> *I had my care in [hospital 1 – name removed] but had a break of my femur and was treated at [hospital 2 – name removed]. The break was due to cancer and I had a bone scan. They said they would send the results to [hospital 1 – name removed] but this did not happen. Surely with all the technology there should be cooperation and the ability to share info for the benefit of the patient*. (Female, aged 51-65 years, 2013 CPES)

> *The communication between departments was appalling e.g. no one told scan unit that I needed a scan, the ward knew and the doctors knew but I waited 2 days in hospital as no appointment was made. Also I was asked to come into hospital at 10am Tuesday because of indications from a blood test. I was told at 5pm Monday the previous evening that I needed a blood transfusion. I did not receive the transfusion until 4am on Wed*. (Female, aged 51-65 years, 2013 CPES)

Patients' comments reflect increased stress and confusion associated with what they perceived to be poor information sharing and communication between agencies involved in their care. In some cases, this was associated with perceptions of delays to treatment and/or poorer outcomes/prognosis.

3.7.5 Follow-up investigations

Patients also provided comments relating to follow-up investigations occurring after a period of treatment, the majority of which were negative. These comments tended to focus on absent or what patients felt to be inadequate follow-up investigations following completion of treatment.

> *When I had my final check-up for the previous breast cancer treatment, I feel it would have been a wise precaution to have had a CT scan then, so that any spread of the cancer could have been detected. I had a mammogram and an examination but the spread to the liver and bones would not have been detected through those*. (Female, aged 51-65 years, 2010 CPES)

> *Previously, I attended the [name removed] hospital, with a tongue ulcer for a period of nine years. I had only ever had one biopsy at the start, apart from the final one, which showed the ulcer to be malignant. Even though on my notes it was stated I needed another biopsy over a year before. If the consultant and his team had performed their job correctly I would not have needed the first operation to the extent it was done on my tongue and the second one on my neck*. (Female, aged 51-65 years, 2010 CPES)

> *Yes. The follow up after chemo/surgery/chemo/radiotherapy involved 3 monthly then 6 monthly visits with only superficial examination and history-taking. During that two year period, I developed spinal and liver secondaries that were not detected until I had clinical problems (bone pain). By that time, the tumours were widespread. Had follow-up included a routine CT scan/s at relevant points, the secondaries would have been picked up much earlier, and treatment started much earlier. I don`t know whether it is different now but, if not, monitoring needs to be more thorough*. (Female, aged 51-65 years, 2011-12 CPES)

> *September 2005 stage 2 oestrogen fed breast cancer. Lymph glands clear. Lumpectomy and radiotherapy. I asked about chemotherapy and was told I did not need it. I was well for 2 and a half years, then felt my health was slowly going down. At my 4 year check-up I told my Macmillan nurse that I thought the cancer had come back in my ribs and sternum, she said no way had it come back and sent me for my 4th year mammogram, she told me a few weeks later it was clear. April 2010 I was taken to another hospital as a 999 after I collapsed, x-rays showed I had cancer in my lungs and sternum. A letter has been sent to the hospital. I feel if I had had chemo at the start I would possible not be terminal now. Mammograms only show cancer is no longer in the breast, it does not show up secondary cancer*. (Female, age unknown, 2011-12 CPES)

> *I felt that once a cancer operation has been done, the follow up should be no later than 3 months after the date of operation. In my case it was done 9 months (CT Scan) and 10 months (MRI Scan) later which revealed a 2nd cancer!* (Female, aged 76+ years, 2013 CPES)
>
> *My diagnosis was delayed being originally discharged by the consultant for three months when I contacted my GP again when I felt I should have had a follow-up appointment. They then decided to give me a mammogram and found the cancer. I then thought this very remiss*. (Female, aged 76+ years, 2013 CPES)

Comments in this sub-category indicate that some participants perceived their follow-up regime to be less rigorous or careful than they would have wished, in some cases where expected or desired procedures were not conducted. Negative comments often linked to perceptions that recurrence could have been detected earlier, in some cases with negative implications for patient outcomes/prognosis.

3.8 General Practioners (GPs)

3.8.1 Overview

In total, 963 (10.4%) comments described experiences with general practioners (GPs) (Table 9). Findings indicate a higher proportion of negative comments compared with positive responses, with the ratio of negative to positive comments remaining broadly stable across the three periods of observation (see table 1). The ratio of negative to positive comments was higher for patients with CUP than for respondents to the WCPES (i.e. 2.06 : 1 vs. 1.53 : 1). A slightly higher percentage of patients with CUP also made comments about GP care compared with the WCPES respondents (i.e. 10 % vs. 9%).

Year	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset Coverage (%)
2010	210	113	323	1.86	10.6
2011-12	219	110	329	1.99	10.4
2013	220	91	311	2.41	10.1
Total	649	314	963	2.06	10.4

Table 9 - Breakdown of comments on General Practioners by period of observation.

Comments relating to experiences with GPs have been divided between those that were pre-diagnosis and those that were post-diagnosis (Table 10). The following two sections discuss first positive comments regarding GPs and then negative comments.

3.8.2 Negative comments relating to GP care.

Pre/diagnostic phase.

Speed of diagnosis and/or referral for further investigations

The greatest number of comments for a specific area in GP care related to *speed of diagnosis and/or referral for further investigations*. Negative comments often indicated months and sometimes years of presentation to GP services with cancer symptoms before diagnosis and/or referral.

> *I didn't receive any support from my GP. I went to see them several times over three months as my back was getting worse. They just kept fobbing me off with painkillers. They made me feel I was wasting their time*. (Female, aged 55-64, 2010 CPES)
>
> *My GP failed to diagnose my cancer, even though I had the symptoms for over 2 years. It wasn't until I changed GP and was sent for a scan that cancer was discovered*. (Male, aged 65-74 years, 2010 CPES)
>
> *GP took 18 months of me going with symptoms to refer me. Not happy with GP*. (Female, aged 55-64 years, 2011-12 CPES)
>
> *My GP`s insistence about not having an MRI scan. Would not book me one although I was visiting GP at least 2 x a week in pain! I think some GP`s ignore symptoms, but if the patient*

Year	Area	Category Description	Negative comments (n)	Positive comments (n)	Ratio (n : 1, negative-to-positive)	Total comments (n)
2010		Miscellaneous	9	74	0.12	83
	Pre/diagnostic	Speed of GP referral for further tests.	83	22	3.77	105
		Misdiagnosis of presenting symptoms, including 'missed' cancers where no other formal diagnosis was given.	48	0	-	48
		GP knowledge of and/or action in relation to a previous history of cancer at the pre/diagnostic stage	12	0	-	12
	Post-diagnostic	Communication between GP and secondary care services in the post-diagnostic phase	41	5	8.20	46
		Care in the post-diagnostic phase	14	12	1.17	26
		Communication between GPs and patients in the post-diagnostic phase	3	0	-	3
	Column Totals		210	113	1.86	323
2011-12		Miscellaneous	11	65	0.16	76
	Pre/diagnostic	Speed of GP referral for further tests.	76	20	3.85	96
		Misdiagnosis of presenting symptoms, including 'missed' cancers where no other formal diagnosis was given.	52	0	-	52
		GP knowledge of and/or action in relation to a previous history of cancer at the pre/diagnostic stage	20	0	-	20
	Post-diagnostic	Communication between GP and secondary care services	28	7	4.00	35
		Care in the post-diagnostic phase	21	11	1.91	32
		Communication between GPs and patients in the post-diagnostic phase.	11	7	1.57	18
	Column totals		219	110	1.99	329
2013		Miscellaneous	28	46	0.61	74
	Pre/diagnostic	Speed of GP referral for further tests.	76	24	3.17	100
		Misdiagnosis of presenting symptoms, including 'missed' cancers where no other formal diagnosis was given.	61	0	-	61
		GP knowledge of and/or action in relation to a previous history of cancer at the pre/diagnostic stage	15	0	-	15
	Post-diagnostic	Communication between GP and secondary care services	16	15	1.07	31
		Care in the post-diagnostic phase	16	3	5.33	19
		Communication between GPs and patients in the post-diagnostic phase.	8	3	2.67	11
	Column totals		220	91	2.41	311
Total			649	314	2.06	963

Table 10 - Subcategories of comments on GPs by period of observation.

> *visits for a period of 6 months complaining of the same thing, I think more specialist consultants and scans should be a priority*. (Female, aged 45-54 years, 2011-12 CPES)
>
> *Mr GP practice completely failed in their duty of care. It took 14 months before I was sent to a specialist - all be it the wrong one - but he did offer me an x-ray there and then. This consequently lead to my diagnosis of lung cancer. Even after my operation for a lung removal I was offered 3 week wait to see my GP - my priority was not considered high*. (Female, aged 55-64 years, 2013 CPES).
>
> *I wish my original GP had listened properly over the months I complained about weight loss (over 2 stone). Instead I had to change my GP who fast tracked me into hospital where a scan showed metastasized tumours*. (Female, aged 75-84 years, 2013 CPES)

Lack of willingness to refer for further investigations was a significant feature of many patient comments, a trend also observed in previous work on the 2013 WPCES (Bracher et al., 2014).

Misdiagnosis of presenting symptoms, including 'missed' cancers where no other formal diagnosis was given.

Comments also highlighted what patients described as misdiagnosis by their GP that was later found to be inaccurate upon discovery of their cancer.

> *GPs said it was a hernia when it turned out to be bowel cancer. The hernia op was done privately for speed. NHS ran out of cash in late 2006. The private doctor demanded I had a CT scan privately for speed NHS far too slow. (This was before [hospital name removed] too over). I was immediately put on (consultant's name removed) op list and the op was done immediately after the private scan. GP never involved or skilled enough*. (Male, aged 65-74 years, 2010 CPES)
>
> *When I first went to the GP in 2002 about my pains I was told they were growing pains/and that everyone has funny pains sometimes I complained about my pain for 2-3 years and was basically ignored. It was only when I went to university and went to the university doctor that I was taken seriously and consequently diagnosed - too late, as it had spread*. (Female, aged 25-34 years, 2010 CPES)
>
> *I was disgusted when, after a laparoscopy in [date removed], I was told that my cancer was still `borderline`. Following 3 more months of feeling unwell, my GP eventually told me I needed to see a counsellor as I was `missing my mother`, who had died in April. After 2 more weeks I went back to another GP to question why no other follow up had been done on my fluid in abdomen and lungs back in [date removed], prior to laparoscopy. It was only then that I was sent for a scan and it was the radiographer that asked, `are you being treated for this?* (Female, aged 45-54 years, 2011-12 CPES)
>
> *Being told initially by GP that `symptoms` ie voice hoarse, sore throat for 6 weeks would eventually go away…If it wasn't for quick thinking of another G.P. possibly cancer would have spread a lot more*. (Female, aged 55-64 years, 2011-12 CPES)
>
> *Very upset that I have to call the GP, a couple of times a week for 5 weeks, my pain getting worse by the day. My wife asked on a couple of visits if I could have x-ray, blood tests, GP said nothing wrong with me, it was just back ache. In the end my wife took me to A&E. She had to get me into wheelchair from the car. I was in terrible pain. Within 1 hour of A&E I had all tests and straight onto a ward, my wife was very upset to be treated like this*. (Male, aged 75-84 years, 2013 CPES)

> *This cancer was misdiagnosed for more than 2 months before my GPs suggested an x-ray. They simply did not take me seriously, and diagnosed tendonitis, without even examining me (2 visits this happened) I had at least 6 visits which were pointless. It seems to have been a case of gross group incompetence, at least 3 GPs were seen over the period. I have since*
>
> *changed my GP and am now entirely satisfied with the new group*. (Female, aged 75-84 years, 2013 CPES)

Concerns within this group focused on GP interest in presenting symptoms, and lack of knowledge and/or competence in relation to cancer.

GP knowledge of and/or action in relation to a previous history of cancer at the pre/diagnostic stage

A small number of patients reported experiences of delays and/or misdiagnoses, and gave comments suggesting that their previous history of cancer was not factored adequately into their care at this stage of the cancer journey.

> *I had breast cancer 13 years ago originally. When it was found that a lump under my arm (which had been there for several years) was cancerous, the hospital care was excellent. The GPs had kept telling me it was a cyst and only referred me back to the hospital after my insistence that they did. This protracted delay could have cost me my life and I feel aggrieved about this*. (Female, aged 55-64 years, 2010 CPES)
>
> *GPs should be more aware of the likelihood of recurrence of cancer and be quicker to carry out appropriate tests. It took 9 months after my 1st visit to the GP for my cancer to be diagnosed, despite the fact I had already had cancer twice. And then it was by chance a physiotherapist took one look at me and a bone scan and immediately made a referral*. (Female, aged 65-74 years, 2010 CPES)
>
> *I found one of my GP`s not very good. [date removed] kept on going to my GP because I had really bad pain in my right hip, had to go to A&E twice. Told my local GP wanted a scan, because of my history of breast cancer, he refused. This happened on three occasions, on the 4th time managed to see a locum, she could see how much pain I was in, I couldn`t hardly walk. She ordered a scan straight away, I found out that I had cancer in my right femur and seventh vertebrae…I know scans are expensive but if you have a patient that thinks something is wrong they should have the right to request tests to see what the problem is not to be refused and told it's a pulled muscle. The outcome would have been worse if I didn't get another doctors opinion*. (Female, aged 55-64 years, 2011-12 CPES)
>
> *I first went to see my GP about my condition in the January. Given my history of cancer he should of referred me immediately to my consultant, he didn't, he assured me that my condition wasn't cancer but it was muscular. If he had done his job properly I would of been saved 7 months of pain and treated sooner. This could of prolonged my life expectancy by a considerable amount of time*. (Female, aged 45-54, 2011-12 CPES)
>
> *I visited my GP Dr [name removed] for over a year with a lump in my remaining breast and despite previously having a mastectomy for breast cancer in my other breast he did not refer me for a mammogram. I feel that his negligence in failing to refer me for further investigation & treatment lead to the disease spreading*. (Female, aged 65-74 years, 2013 CPES)

> *The treatment I receive from the chemo unit is very good. However my GP did not listen to me when I first presented with symptoms which were obvious that my cancer had returned. He then referred me to an inappropriate consultant. This farce continued for many months, which I am still angry about*. (Female, aged 55-64, 2013 CPES)

Across all periods of observation, the vast majority of comments given in relation to delayed or mis-diagnosis where a history of cancer was present came from patients who self-identified as having some form of breast cancer.

Post-diagnostic phase

Communication between GP and secondary care services.

Communication between GP and secondary care services was the most populous area of patient comments relating to the post-diagnostic phase of the cancer journey. It is important to note that these comments were often not critical of GP services *per se*, but of the information provided to them by secondary services.

> *Not enough contact between hospital doctors and your own GP. My GP was not given all test results and not told about different medication I was taking which often clashed with GP's medication and left me to sort it out*. (Female, aged 65-74 years, 2010 CPES)
>
> *Keep my GP informed of all my treatment instead of just my initial diagnosis as they now don't know what is going on apart from what I remember to tell them*. (Female, aged 55-64 years, 2011-12 CPES)
>
> *I should like my GP to be kept informed more quickly of my treatment at hospital. At the moment, information does not get to her quickly enough, so if I want to discuss something with her, she does not have up to date information, sometimes 3-4 weeks behind*. (Female, aged 65-74 years, 2013 CPES)

Comments in this section reveal a lack of continuity between GP and secondary care, with consequences for medication during the treatment phase, and support offered by the GP due to inadequate knowledge of details relating to individual patient treatment within secondary services.

GP care in the post-diagnostic phase.

The other major area of negative comments relating to the post-diagnostic phase of care was in relation to care provided by GP services.

> *The attitude of my GP could be better. He does not seem interested in the cancer diagnosis and cannot answer the questions I have put to him*. (Female, aged 55-64, 2010 CPES)
>
> *My GP. doesn`t want to (or doesn`t feel he needs to) have any involvement in my condition. It felt as if the moment that I was under somebody elses care, that he didn`t have to bother. My original symptoms were misdiagnosed by him originally, so maybe he doesn`t really understand the specifics of my disease*. (Male, aged 45-54 years, 2011-12 CPES)
>
> *My GP practice were initially very helpful but as I am never able to see the GP there is no continuity of care which means I end up having to explain my terminal condition and current treatment each time I attend. Even getting appropriate pain relief prescribed by my GP is an unresolved/on-going matter and were it not for the hospital being very helpful on this point, I would have been left without pain relief!* (Female, aged 45-54 years, 2013 CPES)

Lack of continuity in care between GPs, as well as poor GP knowledge of conditions were prominent features of comments in this area. In addition, some patients perceived a lack of GP interest in their care in the post-diagnostic phase.

3.8.3 Positive comments relating to GP care.

The majority of positive comments in relation to GP care were general (e.g. 'GP excellent') or miscellaneous. The remainder of more specific comments related to *speed of diagnosis and/or referral for further investigations.*

Speed of diagnosis and/or referral for further investigations

Numbers of patients providing positive comments in this area mirror concerns expressed in the corresponding negative comments.

> *I was very pleased with the original speed of diagnosis and the consequent action taken for treatment from GP to specialist at Torbay*. (Female, aged 65-74 years, 2010 CPES)
>
> *From going to my own GP I was seen quickly and my cancer breast cancer found everyone involved very helpful*. (Female, aged 65-74 years, 2010 CPES)
>
> *Between seeing my GP with original concern and getting appointment at [hospital name removed], less than 36 hrs.! How can I fault that!* (Female, aged 45-54 years, 2011-12 CPES)
>
> *It was very good. The moment the G.P. saw me I was rushed to hospital. had immediate tests and was operated on a few days later. My cancer care I cannot see how it could be bettered*. (Male, age unknown, 2011/12 CPES)
>
> *After having breast cancer over 15 years ago it has not come back in my bones. This was first diagnosed as osteoporosis and due to a vigilant GP has now been correctly diagnosed since then, after being referred to oncology I can only praise the treatment the Oncology Department and Orthopaedic Department have given me*. (Female, aged 55-64, 2013 CPES)
>
> *My GP has been brilliant in every way. Patient, kind, thorough and perceptive, he quickly concluded that my diverse symptoms were related and, suggesting cancer, requested an urgent referral to hospital. He has continued to support me with a home visit and phone calls*. (Female, aged 65-74, 2013 CPES)

Patients often praised the speed of treatment and/or referral, as an aspect of an overall experience of good care across the cancer journey. Taken together with the negative comments, this suggests that GP contact during the diagnostic phase is important not only at this stage of the cancer journey but can provide a foundation of confidence for the journey that follows.

3.9 Consultants

3.9.1 Overview

In total, 481 (5.2%) comments described experiences that related to consultant doctors (Table 11). Findings indicate a higher proportion of positive to negative comments, which remained broadly stable across the three observation points. The ratio of negative to positive comments was higher for patients with CUP than for respondents to the WCPES (i.e. 0.41 : 1 vs. 0.18 : 1). Negative comments tended to be more specific than positive responses, with 186 (38.7%) being miscellaneous or general in nature (e.g. 'excellent consultant').

Year	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset Coverage (%)
2010	39	88	127	0.44	4.1
2011-12	51	156	207	0.32	6.6
2013	49	98	147	0.50	4.8
Total	139	342	481	0.41	5.2

Table 11 - Breakdown of comments on consultants by period of observation

Other comments in this category related to communication and interaction between patients and consultants, the accessibility of consultants and continuity with which specific consultants were involved with the care of patients (Table 12).

3.9.2 Manner of communication between consultants and patients

The manner of the communication between patients and consultants appeared to be closely linked with the level of information they provided. This may be because patients and their families mainly interact with consultants in the consulting room or following investigations when they are providing information about the patient's condition and treatment. It was clear from the data that being treated respectfully and as a 'person', rather than as a 'combination of symptoms', was at the heart of what made many experiences with consultants 'positive'. Other features of successful communication with consultants includes their readiness to listen to the patient concerns and to answer questions fully and clearly.

> *My oncologist doctor, very positive but straight talking, treats you like a person and makes you feel like he genuinely cares about you and the outcome. Very knowledgeable, gives you lots of confidence*. (Female, 51-65 years, 2010 CPES).

> *My oncologist is great. Always willing to explain details to me regarding my results, tests, next steps etc. she makes me feel that there really is a future*. (Male, 51-65 years, 2010 CPES).

> *My doctor has been brilliant, very understanding, thorough and dependable. In a very difficult time and situation have real faith in her. She understands the need to communicate when everything is so uncertain. I was tested with numerous scans etc. very quickly. Doctor is also good at not pushing me for treatment for the sake of it, but wants me to live a normal life as possible. I think that she is plugged into my 'unknown primary' type of cancer and trying to work out what can be done*. (Female, 51-65 years, 2010 CPES).

Year	Category description	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	(General or miscellaneous)	0	44	44	0	1.4
	Manner of communication between consultants and patients	25	42	67	0.59	2.2
	Accessibility of consultants	7	1	8	7	0.2
	Continuity of consultants	7	1	8	7	0.2
	Column totals (2010)	39	88	127	0.43	4.2
2011-12	(General or miscellaneous)	0	109	109	0	3.0
	Manner of communication between consultants and patients	27	44	71	0.61	2.2
	Accessibility of consultants	11	0	11	11	0.3
	Continuity of consultants	13	3	16	4.3	0.5
	Column totals (2011-12)	51	156	207	0.32	6.6
2013	(General or miscellaneous)	0	45	45	0	1.4
	Manner of communication between consultants and patients	29	51	80	0.56	2.6
	Accessibility of consultants	11	1	12	11	0.4
	Continuity of consultants	9	1	10	9	0.3
	Column totals (2013)	49	98	147	0.50	4.8
Total		139	342	481	0.40	4.9

Table 12 - Subcategories of comments on consultants by period of observation.

> *Dr [name removed] has always treated me with both dignity and respect, and answered my questions truthfully but with realism tinged with optimism*. (Female, 51-65 years, 2013 CPES).

> *My oncologist has always answered my questions carefully and fully and I have never been hurried or felt I wasn't listened to*. (Female, 51-65 years, 2011-12 CPES).

> *My oncologist has always listened to my concerns and seems to understand me as a person – (not 'a set of cancer symptoms')*. (Male, 66-75 years, 2013 CPES).

When consultants were approachable, it was much more likely that patients would be involved in the decision-making when it came to their treatment.

> *I have also appreciated since having secondary breast cancer the opportunity to discuss options with the consultant oncologist and to steer treatment regimens accordingly to what I am aiming to do, and priorities I have*. (Female, 51-65 years, 2011-12 CPES).

> *My oncologist will ring me at home to discuss any changes that may be made in my treatment before my next appointment. She has also fitted me in at the end of her clinic if I have a worry I need to discuss*. (Male, 66-75 years, 2011-12 CPES).

Comments describing negative experiences with consultants characterised them as unapproachable, not concerned to answer questions, listen to concerns or provide information. In short, not treating patients as persons, with respect and consideration.

> *Last time I had a scare the male oncologist that I saw (not my normal oncologist) was very reluctant to listen to what I was saying. We are not just objects, we are humans and should be listened to not just told what is going to happen and decisions made together*. (Female, 66-75 years, 2011-12 CPES).

> *The op did not go well as my cancer was too extensive to remove. On waking up, of course, asked how it had gone. The doctor in charge (I presume a registrar – he did not introduce himself) would not answer my questions. Later when he did the ward round he was whispering to his colleagues … 'cut and shut'. This was a terrible experience. No answers and then you hear such a terrible phrase. Overall appalling treatment yet here I am [detail removed] later being treated by my oncologist and feeling OK. This doctor made things far, far worse than they needed to be. The consultant was slightly more helpful but his counselling skills (concentrate on quality of life) left a lot to be desired. Surgeons should leave it to oncologists. Give news after ops when the patient wants it and be honest without despair e.g. 'we could not remove your cancer because it was too extensive. The next step is to refer back to your oncologist for an opinion as to the next phase of treatment'. It's not difficult*. (Female, 51-65 years, 2011-12 CPES).

> *Some of the appointments with the doctors have left me and my family a little confused. Jargon words were used and there was little room or encouragement for questions. It felt at times that questions asked have been brushed aside*. (Male, 51-65 years, 2011-12 CPES).

> *The consultant and his doctors at [Hospital name removed] where I had my operation were extremely insensitive and did not appear to have any understanding of what an emotional experience it was for me. I feel that they treated me as a statistic, not a human being*. (Female, 66-75 years, 2013 CPES).

> *On three occasions I saw doctor [name removed] – an oncologist and on every one of these consultations I was left feeling he had not bothered to read my notes and was useless at explaining my results/future treatment and answering any of my questions. I got more information from Wikipedia*. (Male, 51-65 years, 2010 CPES).
>
> *The oncologist should have assessed that I could accept more detailed information than he was prepared to give me. Many practioners cultivate a professional Vagueness which avoids some painful issues but is not helpful to the patient*. (Female, 51-65 years, 2011-12 CPES).

Similarly, a poor manner of communication with patients translated into limited involvement for them in treatment decision-making.

> *My choice of treatments was not offered at first. I was initially told that I must have a colostomy, a prospect which I found even more frightening and emotionally disturbing than cancer. The abrupt 'matter of fact' attitude of the surgeon telling me this was also quite unsatisfactory. It was several weeks later that the oncologist first told me that there was an alternative treatment, which I took*. (Female, 66-75 years, 2013 CPES).
>
> *The patient should be listened to. They know their body best. I had to have a sigmoidoscopy. I knew this would fail and said so verbally and in writing. Sadly no one listened. This incident is under a complaint procedure. Unfortunately I have heard nothing about the matter. It is likely it has been forgotten. Whoever is supposed to be looking at the complaint should also be criticised for their lack of handling of the matter. I have been advised that I have 1 or 2 years to live. Are they waiting for me to die first???* (Female, 51-65 years, 2013 CPES).

Communication could be made more difficult when doctors from overseas had poor English language skills. This could confound patients' difficulties with understanding their condition, leading to increased stress and anxiety.

> *It seems from my experience that whether you see the oncology consultant or a registrar is pure chance. I went well over year without seeing the consultant even though my condition and therefore my treatment was changing. The quality varies greatly. Some are very good. Others seem to find it difficult to answer questions. Some were very difficult to understand because of heavy accent. This increases the stress in what is already a very stressful situation*. (Female, 51-65 years, 2010 CPES).
>
> *One of the doctors was very difficult to understand – language and accent. On a couple of occasions I felt my condition was not explained – details missing and they had to keep going out of the room to find out the answers to my questions*. (Female, 51-65 years, 2013 CPES).

Some patients under the treatment of several consultants, appeared to have very different experiences with each of them.

> *My surgeon was monosyllabic. He removed my lump but later I caught an infection. Therefore he did a mastectomy. Not a good job and I was left with a large dogs ear under my left arm. In the meantime, my consultant clinical oncologist (with whom I have great confidence) is charming and highly intelligent*. (Female, 51-65 years, 2011-12 CPES).

Patients could sometimes find their condition difficult to understand due to apparent disagreements between consultants. This could lead to increased anxiety for patients.

> *Lack of information on diagnosis and the implications of my illness, gone from thinking my prognosis was good, to poor, to excellent, and then bad through. Not being given enough information on secondary brain cancer throughout my NHS experience. Was told by oncologist I only had months to live and 4 weeks later was told by another oncologist this is not the case, confusing and unfair on my family and myself*. (Female, 51-65 years, 2010 CPES).

> *Discrepancy of information being given by surgeon and oncologist of what had been carried out in the operation leaving me feeling very anxious*. (Male, 66-75 years, 2011 CPES).

> *More liaison between surgeon and oncologist. Oncologist was unaware I was having an operation for my cancer*. (Female, 51-65 years, 2013 CPES).

There appeared to be less trust for registrars than consultants. A number of patients reported receiving different information and explanations from registrars than they did from their consultants.

> *The registrars have been a problem. They have been extremely negative and insensitive. Irresponsive. The first one implying I had a few months to live without all the results of my tests coming in. once all the results were in my condition wasn't as disappearing. Bedside manners of registrars could be greatly improved*. (Female, 66-75 years, 2011-12 CPES).

> *Lack of consistency, e.g. mid-way through chemo, after scan, doctor said all was fine and to continue treatment. Next appointment, my 'chief' oncologist said it wasn't responding enough and should be changed*. (Male, 66-75 years, 2011-12 CPES)

> *Two registrars were very publically in disagreement about my treatment*. (Female, 51-65 years, 2013 CPES).

> *Junior doctors need to have more information from the oncologist whilst training before seeing the patient. I have found they do have your notes, but do not seem to be aware of what I happening at the present time. They seem to rely on us the patients to tell them what is going on*. (Female, 51-65 years, 2013 CPES).

Communication could also be compromised when patients were transferred from one consultant team to another. Such transfers could lead to administrative delays to treatment, and patients could feel as if there was no-one responsible for their overall care.

> *Diagnosis could/should have been earlier. Once diagnosed, was delay of six months before operation. I saw an oncologist who informed me that surgery may be possible. I was told by a consultant that surgery was possible and underwent several investigations and scans. I was told that surgery was not possible. I received a telephone call from a different consultant that he could possible operate. Further tests including scans and laparoscopy (under anaesthetic). When I came round from anaesthetic the consultant informed me that the cancer was operable. A week later I was informed by another consultant that he could operate, was 90% certainty it would be successful. Further tests and then a successful operation. The biggest problem was the delay between each appointment and*

> *the administrative structure which means a wait between appointments which causes considerable stress*. (Female, 36-50 years, 2010 CPES).
>
> *There was delay between being told by my GP I was seriously ill + seeing the first consultant. Although this was within the target time it was the most difficult time. Similarly when referred from one consultant to a second consultant, from the second consultant to the oncologist, absolute black holes*. (Male, 51-65 years, 2010 CPES).
>
> *I have cancerous growths and metastases, which have affected various parts of my body and I feel I would like to know that there was one consultant, of the four departments involved, who was having an overview. Holistic management of the cancers which were/are affecting me*. (Female, 51-65 years, 2011-12 CPES).

3.9.3 Accessibility of consultants

A few patients reported that they rarely met their consultants, and were usually seen by registrars or junior doctors. As noted above, participants tended to have less confidence in the information provided by more junior doctors who they sometimes felt were unprepared for consultations.

> *When I have tried to telephone my oncologist's secretary at times the mailbox has been full and I have been unable to leave a message and at other times I have had to wait over a week for a reply to a question, which to me was of great importance*. (Female, 66-75 years, 2011-12 CPES).
>
> *Communication after operation. The surgeon did not come to see me in the week after my operation, despite my request to see him. I also needed more information about the frequency I needed to do physiotherapy and how to progress in mobility – e.g. what progress could be expected/ what to watch out f*or. (Female, 51-65 years, 2011-12 CPES).
>
> *Urology specialist I have not seen. It is always one of his team. They have all my notes but have not had time to read them. Most of the appointment is taken up with me updating them*. (Female, 51-65 years, 2013 CPES).
>
> *I see a different registrar every other week when going for treatment who often say different things, are inexperienced and nervous*. (Male, 51-65 years, 2013 CPES).

3.9.4 Continuity of consultants

For another small group of patients the main problem appeared to be a lack of continuity of the doctors they saw, whether consultants or registrars. Doctors they had not previously met were often unfamiliar with the patient's condition and, again, were frequently unprepared. Consequently, the confidence patients had in their treatment could be diminished.

> *I wish to see the same oncologist each time to give continuity of care and confidence in the treatment given*. (Male, 51-65 years, 2010 CPES).
>
> *The only thing I think could have been improved would have been able to see the same oncologist rather than different one each time. This would enable a relationship could be developed*. (Female, 51-65 years, 2011-12 CPES).

> *I would like to see the same oncologist in outpatient clinics at the moment. I see a different doctor every time I go. Most of the time they read up my notes prior to the consultation and are obviously not familiar with my case*. (Female, 51-65 years, 2011-12 CPES).
>
> *Through my 2.5 years of treatment this time I found after the first year I had no continuity as I was seeing a different oncologist at appointments and also I found that many times I was not receiving appointments when I should have been. I think this needs to be improved on as patients should not have to be chasing their appointments*. (Female, 66-75 years, 2011-12 CPES).
>
> *From a patient point of view it would have been much better to have had continuity - by seeing the same consultant/ registrar on each visit. It does not instil confidence when on each follow up visit, one has to repeat what has been done/not done etc. it is clear on each visit that the notes have only been skimmed though. I certainly did not feel I was getting the best medical attention*. (Male, 51-65 years, 2013 CPES).

Overall, however, comments regarding consultants and senior doctors were broadly positive amongst this patient group.

3.10 Nursing

3.10.1 Overview

In total, 2201 (23.8%) comments described experiences of patients with nurses and the quality of nursing care (Table 13). This was the single largest theme amongst comments and is similar in volume to the WCPES 2013, of which 23% (n=1074) of all comments concerned nursing. However, there was a decline in comments from 29.5% of all coded comments in 2010 to 21.8% in 2011-12 and 22.7% in 2013. Moreover, while there was a higher proportion of positive to negative comments at all three observation points, the ratio of positive to negative comments was lower in the subsequent two years following 2010. The reasons for this are not clear. Across all periods of observation, the ratio of negative to positive comments for nursing was higher for patients with CUP in the English CPES than for respondents to the WCPES (i.e. 0.66 : 1 vs. 0.25 : 1).

Year	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset Coverage (%)
2010	340	580	920	0.58	29.5
2011-12	289	399	588	0.72	21.8
2013	284	409	693	0.69	22.7
Total	913	1388	2201	0.66	23.8

Table 13 - Breakdown of comments on Nursing by period of observation

Comments in this theme were broken down under three subcategories, the *quality of nursing care*; *communication and interaction with nurses*; and *nurse staffing levels* (Table 14). Throughout these subcategories, concerns emerged regarding the quality of agency staff, a disparity in the quality of care provided by staff on duty during the weekdays and those staffing night shifts and weekends, and problems with understanding the foreign accents of some nurses from overseas.

3.10.2 Experiences of communication and interaction with nursing staff

Comments relating to the quality of communication between nurses and patients were closely related to the quality of care provided. The majority of comments in this subcategory were positive, with nurses conveying a caring and respectful approach towards participants and meeting their informational needs.

> *I find the nurses very good at their job and made me feel good and explain things in a way I could understand*. (Female, 66-75 years, 2010 CPES).

> *The community nursing staff from the health centre had to dress a deep wound in my groin for three months, starting daily and easing off as I healed. They were understanding, supportive and encouraging and I cannot speak highly enough of them*. (Male, 51-65 years, 2010 CPES).

However, on many wards there were a minority of nurses who could be rude and disrespectful.

> *One nurse in [unit name removed] was uncaring, verging on hateful and cruel. She obviously had a personal problem and was the only bad part of my entire treatment*. (Female, 51-65 years, 2013 CPES).

The quality of communication and interaction between nurses and patients was also closely linked to the provision of information regarding individuals' condition and treatment. For some patients this was less than satisfactory.

Year	Category description	Sub-category description	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset Coverage (%)
2010	(General or miscellaneous)	.	0	58	58	0	1.9
	Communication between patients and nursing staff	Quality of information	35	64	111	0.54	3.6
		Manner of nursing staff	125	218	338	0.57	11.1
	Experience of nursing care		134	240	369	0.55	12.1
	Nursing staff levels		46	0	46	46	1.5
	Column totals (2010)		340	580	920	0.58	29.5
2011-12	(General or miscellaneous)		0	29	29	0	0.9
	Communication between patients and staff	Quality of information	33	84	117	0.39	3.7
		Manner of nursing staff	106	122	228	0.86	7.2
	Experience of nursing care		130	164	294	0.79	9.3
	Nursing staff levels		20	0	20	20	0.6
	Column totals (2011-12)		289	399	688	0.72	21.8
2013	(General or miscellaneous)		0	26	26	0	0.8
	Communication between patients and nursing staff	Quality of information	38	98	136	0.38	4.4
		Manner of nursing staff	110	129	239	0.85	7.8
	Experience of nursing care		118	156	274	0.75	8.9
	Nursing staff levels		18	0	18	18	0.5
	Column totals (2013)		284	409	693	0.69	22.7
Total			913	1388	2201	0.66	23.8

Table 14 - Subcategories of comments on nursing staff by period of observation.

> *Maybe doctors and nurses doing more to keep relatives (my husband) more informed about your treatment on the wards. Rather than having to chase around after a senior nurse etc*. (Female, 51-65 years, 2013 CPES).

A fundamental part of good communication skills is the ability to listen to patient's concerns, and this was reportedly lacking in some interactions between nursing staff and participants.

> *Some nurses need to listen more to the patients they are caring for and listen to their needs and not go on their own judgement. When they say they are in pain and not just put it down to anxiety. I was that person and I was in pain and needed pain pills and not to be told it was all in my mind. I was more than willing to swap places. Look Listen & Learn* . (Female, 51-65 years, 2010 CPES).

> *Staff in both [departments removed] could have at least listened to me when I tried to explain my [details removed], only one doctor listened to me and was helpful. I am very upset about the way I am treated; I am a person in my own right, not just another number!* (Female, 36-50 years, 2011-12 CPES).

Poor language skills of some foreign members of staff were reported. Some nurses either had poor English skills or heavy accents that participants found difficult to understand.

> *Some nurses need improving. It's no good having a nurse to look after you who can't speak English*. (Male, 51-65 years, 2010 CPES).

> *It is essential that doctors and nurses from abroad have a good command of the English language*. (Male, 51-65 years, 2010 CPES).

> *I could not understand the foreign language of some of the nurses*. (Female, 66-75 years, 2010 CPES).

> *The nursing staff were very poor. Mainly due to lack of numbers and language difficulties. Staff were constantly in dispute with each other even in front of patients*. (Female, 51-65 years, 2011-12 CPES).

> *Ethnic mix which introduced some very slight misunderstandings for a short time*. (Female, 51-65 years, 2011-12 CPES).

Communication was sometimes lacking between nursing staff and other health professionals, which could have a detrimental impact upon the well-being of patients.

> *Doctors and nurses should communicate about each patient prior to arriving at the bedside*. (Female, 51-65 years, 2013 CPES).

> *Between nurses and doctors could be better communication. It's the nurses who seem a bit slow and sometimes don't even pass your concerns on (this is when I have stayed in hospital*). (Female, 51-65 years, 2013 CPES).

> *There does not seem to be much communication between the doctors & nurses*. (Female, 51-65 years, 2010 CPES).

Communication has as much to do with non-verbal skills and the need to appear approachable.

> *Some nurses are unfriendly and un-smiling. They make you feel that you are a nuisance, they talk over you, as if you are not there. I know that they have a busy job to do but when you are ill and scared, a smile and a cheery word goes a long way to making you feel better. As an [occupation removed] this makes me sad and a little angry. They are in the caring profession*. (Female, 51-65 years, 2011-12 CPES).

Patients described some nurses as indiscreet with information about their conditions and did not sufficiently respect their right to privacy.

> *One nurse is particularly 'loud' and the whole of the waiting room has heard about my medical history/diagnosis - not pleasant*. (Female, 51-65 years, 2010 CPES).

> *My room was very near the central nurse station and could hear them talk about myself and other patients. I even heard someone say outside my door (discussing me) `it`s such a shame - she is so young` as if I was going to drop dead that day*. (Female, 51-65 years, 2011-12 CPES).

3.10.3 Experiences of care provided by nursing staff

Overall, the majority of patients reported good experiences of nursing care. However, the level of care provided by individual nurses on wards could sometimes be variable, and some could be brusque and rude.

> *The nursing care is very patchy. There are some excellent nurses and there are some nurses who should not be nursing*. (Female, 51-65 years, 2010 CPES).

> *Nursing staff - very hit and miss. Poorly led, overworked and focussed too much on tasks rather than care*. (Female, 51-65 years, 2013 CPES).

> *The quality of individual members of the staff team was good. Unfortunately it was not consistent with variation among junior doctors, qualified nurses and nursing assistants*. (Female, 66-75 years, 2013 CPES).

> *Most nurses, whilst being technically excellent were not quite so concerned with the comfort of the patient as the more experienced and mature [and senior] nurses/sisters*. (Male, 66-75 years, 2011-12

> *Most of the nurses are caring and so kind although there always seemed to be the odd ones on duty you tried to avoid!* (Female, 36-50 years, 2013 CPES).

> *Nurses on the wards could do with more training relating to patient care. Some were blatantly rude and outright unhelpful and rude on more than several occasions*. (Female, 51-65 years, 2013 CPES).

Patients reported that on occasion sub-optimal levels of care could be quite concerning with patients left without basic care or prescribed medication and left in pain. Their relatives sometimes had to complain or provide the care themselves.

> *Some of the nursing care on the ward was appalling. One day I was left in excruciating pain and it was late into the afternoon before this was controlled. Some of the nurses had no respect or appeared to care for their patients*. (Female, 36-50 years, 2010 CPES).

> *After I'd left intensive care although I felt VERY ILL. No help was given to help me to wash or shave. It was a case of if you could look after yourself fine if not tough. My wife had to wash and shave me in the end*. (Female, 51-65 years, 2011-12 CPES).

> *Care whilst on the ward after my lumpectomy was awful. My needs, especially concerning the drain from my breast. I left hospital with an infection of the incision under my arm-pit caused by a nurse scratching me when she helped me off the toilet to walk to my bed. My drain was removed from my breast without painkillers. Excruciatingly painful and the nurse accused me of having a low pain threshold when I cried out in pain. I could not wait to get off that ward. I was advised by my Macmillan nurse to write a formal letter of complaint about my care on the ward but I did not have the mental strength during my chemotherapy, radiotherapy etc*. (Female, 66-75 years, 2011-12 CPES).

> *I wasn't sure about the system of ringing bells for nurses. I think sometimes I expected to be done automatically for example dressing wounds and making sure you'd sorted yourself out properly with washing, eating, taking exercise when feeling better were not checked*. (Female, 51-65 years, 2013 CPES).

> *The nursing staff completely failed to give me prescribed treatments appropriately: i.e. the doctors attached an IV [words unreadable] for eight hours in spite of the doctor being surprised that it had not been attached following a six hour period. Furthermore, nursing staff failed to give me IV anti-nausea treatment in spite of my many requests for it, which resulted in a severe vomiting at 2am, but even the nursing staff failed to give me this treatment before breakfast and lunch, in spite of many requests, which resulted in me being unable to eat their meals*. (Male, 51-65 years, 2013 CPES).

> *On one of my stays in hospital following my operation, I felt that some of the nursing staff were very abrupt and got the impression they weren't bothered about caring for anyone, also there was real mix-ups about medication and this really bothered me – correct medication notes were not kept and a lot of confusion with different staff members not knowing what the other was doing*. (Female, 51-65 years, 2010 CPES).

Patients reported that some nurses were not following standard procedures for hand washing, and expressed concerns of possible infection.

> *As a nurse for 20 years I was still staggered at the way staff did not clean their hands at appropriate times. Needing daily dressings, I thought that the aseptic technique was disregarded and several time pointed out to the nurses that their sloppy way of dressing my PICC line put my health at great risk. Also, dressings were being done at the same time as ward cleaning. Surely ward cleaning can wait for dust to settle before patients dressings would help bring down number of infections*. (Female, 51-65 years, 2010 CPES).

> *I had to request on a number of occasions that the nurses wash their hands. Supervision: on one occasion nurse did not do as requested by surgeon and change dressing (although she told him she would) I had to remind her. Nurse on next shift did the dressing in the end*. (Female, 51-65 years, 2013 CPES).

A proportion of patients reported that care at night and at weekends could sometimes be of a lower standard than during the day. This standard was sometimes linked with the use of agency nursing staff and sometimes with understaffing.

> *Some of the weekend and night staff were not as good as the day staff*. (Male, 51-65 years, 2010 CPES).
>
> *The majority of the nurses at [hospital name removed] are appalling – lazy, cruel and careless when administering medication, making mistakes 25% of the time*. (Female, 66-75 years, 2011-12 CPES).
>
> *Nursing staff on men's surgical, poor at night and very poor on weekend nights (no interest or compassion in patients)*. (Male, 51-65 years, 2010 CPES).
>
> *My confidence in night time nursing staff is significantly lower than that of the day staff*. (Female, 51-65 years, 2010 CPES).
>
> *Some nurses were excellent, but a couple were uncaring, rude, abrupt and unprofessional. The ward seemed under staffed and the night shifts attitude seemed to be to leave problems, if possible, to the day shift*. (Male, 51-65 years, 2013 CPES).
>
> *Possibly the number of nurses, the bank nurses, although mostly good, were once or twice less knowledgeable and in one case less caring than regular nurses*. (Female, 51-65 years, 2011-12 CPES).

3.10.4 Nurse staffing levels

In total, 84 patients provided comments regarding nursing levels, almost all of them describing conditions of understaffing. Nursing levels were described as 'insufficient' and 'inadequate', with nurses' consequently 'rushed off their feet' and unable to provide necessary care. Concerns were raised about the safety of patients in these conditions as well as basic care not being provided.

> *In the three or four weeks I spent in hospital in the past year there have never been enough nurses on duty on the wards. The standard of nursing care in general is far too poor because of chronic understaffing*. (Female, 51-65 years, 2010 CPES).
>
> *More nursing staff on the chemotherapy day unit. Often they were short staffed due to volume of people attending the unit for chemotherapy. The care was not compromised but the staff were often rushing around to meet the demands*. (Female, 51-65 years, 2011-12 CPES).
>
> *The nursing staff at [Hospital name removed] were very hard working. However I felt that the chronic staff shortage was so bad on occasions that the safety of both staff and patients were put at risk. A 12 hour shift with a 20min and 30min break in total. At the end of the shift it was noticeable that staff were exhausted*. (Female, 66-75 years, 2013 CPES).
>
> *Due to the lack of nursing staff I found it essential to have a friend with me as when I was put on the drip I was just left there. On 2 occasions I had a bad reaction & my friend had to tell a nurse. If my friend wasn't there the reaction could have been a lot worse*. (Female, 51-65 years, 2013 CPES).
>
> *It would have been nice to have had more nurses in the evening and night on the ward as they had so much to do. I was fortunate in that I'm quite independent. Some of the elderly were waiting for*

> *attention as involved with other patients. They were always bright and cheerful and apologetic for any delays*. (Male, 51-65 years, 2013 CPES).

> *If any patient needed extra attention from the nurses it left the number so depleted the remaining patients had to wait a considerable time before they were attended to*. (Female, 66-75 years, 2013 CPES).

Very occasionally, patients suggested that although under-staffing was a common complaint, it was not always the case.

> *They always say there isn't enough staff to help with your general care but they still seem to find time to sit around talking. Sorry but you are asking for my comments*. (Female, 51-65 years, 2011-12 CPES).

Overall, however, reported experiences with nurses amongst this patient group were broadly positive.

3.11 Clinical nurse specialists (CNSs)

3.11.1 Overview

In total, 268 (2.9%) comments described experience of clinical nurse specialists (CNSs) across three periods of observation (Table 15). A higher proportion of positive comments were found compared with negative responses. There were fewer comments relating to CNSs in the first year of CPES as in subsequent years, but the ratio of negative to positive comments remained relatively consistent, and was broadly similar to that of respondents to the WCPES (i.e. 0.40 : 1 vs. 0.35 : 1).

Year	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	18	49	67	0.37	2.2
2011-12	31	70	101	0.44	3.2
2013	28	72	100	0.39	3.3
Total	77	191	268	0.40	2.9

Table 15 - Breakdown of comments on CNSs by period of observation

Comments in this theme were broken down under three further categories: general/miscellaneous, communication between patients and CNSs, and accessibility of CNSs (Table 16). Most negative comments (n=55, 71%) related to accessibility of CNSs rather than issues concerning the quality of service provided.

3.11.2 Positive comments relating to CNS care

Very few patients used the term ‘key worker’, indicating it is a term with which patients may not be familiar. Nevertheless, positive comments regarding CNSs indicated their importance as a point of contact for patients and their families, and for their central role in coordinating care. Comments indicated that CNSs were invaluable for many patients in ensuring that care is joined-up between different clinical teams and departments, providing patients with clear explanations and allaying fears.

> *The clinical nurse specialist has been a tremendous help acting as a point of contact, providing clear explanations and following up delays in receiving appointments*. (Male, 51-65 years, 2010 CPES).
>
> *I found the clinical nurse specialist to be of particular benefit. Speaking to your consultant direct is not easy and can be an intimidating experience. The CNS provides a quick and informal contact when information and / or advice are needed*. (Female, 36-50 years, 2010 CPES).
>
> *Having a specialist nurse who acted as the point of contact for all aspects of my care. She was essential to ensuring that my case was represented at the MDT and to explain the treatment and side effects to me. Whilst all the oncologists I have seen have been excellent they have come and gone – only my specialist nurse has remained a constant presence*. (Female, 51-65 years, 2013 CPES).
>
> *Once when Dr [name removed] had agreed (based on blood results) that my chemo could go ahead, the pharmacist intervened and said I couldn’t. My niece intervened and spoke to the nurse specialist who spoke to Dr [name removed] and the chemo went ahead, which is what I wanted*. (Female, 51-65 years, 2011-12 CPES).

Year	Category description	Sub-category description	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset Coverage (%)
2010	(General or miscellaneous)	.	0	25	25	0	0.8
	Communication between patients and CNSs	Quality of information	4	10	14	0.4	0.5
		Manner of communication	1	14	15	1	0.5
	Accessibility of a CNS		13	0	13	0.07	0.4
	Column totals (2010)		18	49	67	0.36	2.2
2011-12	(General or miscellaneous)		0	29	29	0	0.9
	Communication between patients and staff (manner of staff)	Quality of information	6	19	25	0.31	0.8
		Manner of communication	4	22	26	0.18	0.8
	Accessibility of a CNS		21	0	21	21	0.7
	Column totals (2011-12)		31	70	101	0.44	3.2
2013	(General or miscellaneous)		0	38	38	0	1.2
	Communication between patients and staff	Quality of information	6	14	20	1.5	0.7
		Manner of communication	1	20	21	0.05	0.7
	Accessibility of a CNS		21	0	21	21	0.7
	Column totals (2013)		28	72	100	0.38	3.2
Total			77	191	268	0.40	2.8

Table 16 - Subcategories of comments on clinical nurse specialists (CNSs) by period of observation.

> *Specialist nurse system is very good. She is able to give advice and change appointments if necessary. Advice system is very good and it is re-assuring to know you can get advice 24/7*. (Female, 51-65 years, 2013 CPES).
>
> *I thought the consultations with consultant nurse was more helpful than a consultation with a registrar as the nurse went into more details concerning side-effects*. (Female, 51-65 years, 2010 CPES).

3.11.3 Lack of accessibility of a CNS

The majority (n=55, 71%) of negative comments regarding CNSs related to a lack of access. The lack of a CNS was sometimes blamed for a lack of communication between clinical teams, departments and specialities and between health professionals and the patients and their relatives.

> *I've never been offered the care of a CNS until very recently. I don't think the hospital is holistic enough in its approach – if I ask anyone, except the consultant, about these treatments or therapy they know nothing about them and don't seem willing to find out*. (Female, 51-65 years, 2010 CPES).
>
> *Since my diagnosis with secondary breast cancer I have never been allocated a clinical nurse specialist, nor key worker. I therefore have nobody to contact if I need to discuss any issues or help in accessing support*. (Female, 51-65 years, 2011-12 CPES).
>
> *No specialist nurse for lung cancer. No joined up thinking – not treated as a 'whole body' but my parts divided up amongst specialists*. (Male, 51-65 years, 2011-12 CPES).
>
> *A caring clinical nurse specialist would have been nice. The cancer journey was horrendous really. We felt very isolated and not at all informed in the beginning. I got most of my information on my cancer on the internet. There didn't seem to be anyone to ask and any information we did get seemed vague*. (Male, 51-65 years, 2011-12 CPES).
>
> *It would have helped to have a designated clinical nurse specialist at [hospital name 1] to help with emotional and practical advice. I had one at {hospital name 2}, where I was first diagnosed and I found her support invaluable, but was not offered one at [hospital name 1]. I found it a drawback to keep seeing different doctors and nurses all the time*. (Female, 66-75 years, 2013 CPES).

There was a belief expressed by several patients that with the diagnosis of metastatic cancer they had been 'written off' by the NHS and were not given access to a CNS to save money.

> *I have secondary breast cancer but no nominated breast care nurse. This seems common across the country but does make us feel isolated/written off. Not sure of the figures locally, but secondary cancer specialist nurse would be very useful. I appreciate primary patients' need care and attention, but as a secondary patient, I feel my need is just as great – a phone call once in a while or opportunity to discuss option/concerns*. (Female, 51-65 years, 2013 CPES).
>
> *With secondary diagnosis it felt like I was not saveable and so all the funding went to primary cancer patients*. (Male, 51-65 years, 2013 CPES).

3.11.4 Negative comments relating to CNSs

A few patients (n=23) reported negative comments regarding the manner or effectiveness of the CNS they had been allocated or in the manner with which they interacted with participants.

> *Clinical nurse specialist – not easy to contact. Never spends any time with me and doesn't always have information about operations that I had to have. Not empathetic towards me. Appears to treat patients as a number and offered no real support*. (Female, 51-65 years, 2013 CPES).
>
> *Specialist nurse could have been more professional. Professionals need to tell the truth and not tell patients only part of the problem, this can give people false expectations for the future. Respect needs to be offered to everyone but especially older people*. (Female, 51-65 years, 2013 CPES).
>
> *The cancer care specialist nurse is cold, uninterested and unmotivated*. (Female, 51-65 years, 2010 CPES).
>
> *The nurse specialist has not been very reliable, has promised to do several things and then not done them. This has been something of a problem as I live 70 miles from the hospital.* (Female, 51-65 years, 2010 CPES).

Overall, however, the comments reflect positive experiences with regards CNSs.

3.12 Accident and emergency care

In total, 94 (<0.01%) comments described experiences of accident and emergency (A&E) across three periods of observation (Table 17). Findings indicate a higher proportion of negative comments compared with positive responses, with the ratio of negative-to-positive comments remaining broadly similar across observation points. Comparing data with those from the WCPES, the ratio of negative to positive comments was slightly lower for CUP patients than for respondents to the WCPES (i.e. 3 : 1 vs. 4.12 : 1).

Year	Negative respondents (n)	Positive respondents (n)	Total respondents (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	22	5	25	4.40	0.8
2011-12	22	7	29	3.14	0.9
2013	28	12	40	2.33	1.3
Total	72	24	94	3.00	1.0

Table 17 - Breakdown of comments on accident and emergency care by period of observation.

The majority of negative comments focused on the role of A&E services in the initial diagnostic phase, or periods of waiting when admitted during the treatment phase of the cancer journey.

> *I went to my local GPs surgery 3 or 4 times and was finally referred to the A&E at [name removed] hospital but was sent home without an x-ray and with anti-inflammatory drugs*. (Female, aged 66-75 years, 2010 CPES)
>
> *Being admitted through A&E via cancer doctor was not a pleasant experience. When having to wait several hours before being seen by a doctor after covering letter sent by cancer doctor - conflicting information being given did not then help either. The whole experience from A&E to discharge I would not want to go through again*. (Female, aged 51-65 years, 2010 CPES)
>
> *Sometime before my operation, I went to the A&E department with severe abdominal pain. The doctor prescribed an enema. Nothing came out! In my opinion, any doctor worth his salts should have suspected something more serious than constipation. Not so, I was discharged with no further treatment but to refer to my GP*. (Male, aged 76+ years, 2011-12 CPES)
>
> *Having to go through A&E when I was neutropenic and waiting for hours to be transferred to the ward. They had my notes and knew exactly what was wrong but still carried out further tests on me. This was very stressful*. (Female, aged 66-75 years, 2011-12 CPES)
>
> *At [name removed] healthcare trust I needed to go to A&E after first chemo (on the same day) went in at 8pm left at 2:10am it was dreadful - they have no on-call oncology*. (Female, aged 36-50 years, 2013 CPES)
>
> *Waiting in A&E for 2-3 hours to be seen was very frustrating at times*. (Female, aged 66-75, 2013 CPES)

The smaller number of positive comments focused on aspects of good care provided, sometimes in the presence of other negative aspects such as extended waiting times.

> *[A]fter the 5hr wait I did see an excellent A&E doctor who unfortunately had to apologise for the poor service I received*. (Female, aged 51-65 years, 2010 CPES)
>
> *The treatment I received during chemo when problems occurred and I went to A&E were excellent, everybody who dealt with me was kind and understanding I have no fault whatsoever with them*. (Female, aged 51-65 years, 2011-12 CPES)
>
> *Accident and emergency at the [name removed] was excellent, they took my symptoms seriously and diagnosed the advanced cancer within 24 hours*. (Female, aged 36-50 years, 2013 CPES)

Overall, the comments reflect aspects of dissatisfaction with waiting times and the involvement of A&E services in the diagnostic phase, together with examples of good or excellent care.

3.13 Chemotherapy

3.13.1 Overview

In total, 1132 (12.2%) comments described experiences of chemotherapy across the three periods of observation (Table 18). Findings indicate a far higher proportion of positive comments compared with negative responses, with a slight increase in the ratio of negative-to-positive comments over the three observation points. Comparing data with those from the WCPES, the ratio of negative to positive comments was slightly higher for patients with CUP (i.e. 0.46 : 1 vs. 0.36 : 1). A greater percentage of total patients with CUP gave comments about chemotherapy compared with WCPES respondents (i.e. 12% vs. 7%), possibly indicating the heavier treatment burden faced by patients within this group.

Year	Negative respondents (n)	Positive respondents (n)	Total respondents (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	168	231	399	0.73	13.1
2011-12	128	265	393	0.48	12.5
2013	58	282	340	0.21	11.1
Total	354	778	1132	0.46	12.2

Table 18 - Breakdown of comments on chemotherapy by period of observation

3.13.2 Communication between patients and staff

Comments in this area broke down into two main sub-categories; *quality of information* and *the manner in which staff dealt with patients* (Table 19). The vast majority of comments related to the manner in which staff had dealt with patients, and responses in this section were exclusively positive across all periods of observation.

> *The nurses giving chemo, have been wonderful always cheerful and kind. I really appreciate them*. (Male, aged 66-75 years, 2010 CPES)

> *The specialist chemotherapy nurses who deal with me are extremely well trained in their job and are always friendly and try to help with any problems I might have*. (Female, aged 51-65 years, 2010 CPES)

> *The chemotherapy nurses at [hospital name removed] were truly fantastic on the out-patient ward; great care, attention and their sense of humour made 8 hour BEP chemo sessions fly by*. (Male, aged 26-35, 2011-12 CPES)

> *The care given by the nurses on the oncology department has made my courses of chemotherapy a pleasurable experience with their kindness and personal attention instead of dreading my appointments it became more of a social occasion with a cup of tea, biscuit and a chat*. (Female, aged 76+ years, 2011-12 CPES)

> *Chemotherapy day care nurses were very caring - but they were always short staffed and overworked*. (Male, aged 51-65, 2013 CPES)

> *The staff administering the chemotherapy at the oncology centre were excellent. They had reassuring amounts of experience and expertise. They could be compassionate or cheery and humorous when appropriate*. (Female, aged 51-65 years, 2013 CPES)

Year	Category description	Sub-category description	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	(General or miscellaneous)	.	36	136	172	0.26	5.7
	Communication between patients and staff	Quality of information	9	9	18	1.00	0.6
		Manner of staff	0	86	86	.	2.8
	Chemotherapy treatment environment	.	25	0	25	.	0.8
	Waiting on the day of treatment	.	98	0	98	.	3.2
	Column totals (2010)	.	168	231	399	0.73	13.1
2011-12	(General or miscellaneous)	.	24	151	175	0.16	5.6
	Communication between patients and staff	Quality of information	10	4	14	2.50	0.4
		Manner of staff	0	110	110	0.00	3.5
	Chemotherapy treatment environment	.	19	0	19	.	0.6
	Waiting on the day of treatment	.	75	0	75	.	2.3
	Column totals (2011-12)	.	128	265	393	0.48	12.5
2013	(General or miscellaneous)	.	33	125	158	0.26	5.2
	Communication between patients and staff	Quality of information	15	4	19	3.75	0.6
		Manner of staff	0	91	91	0.00	3.0
	Chemotherapy treatment environment	.	10	.	10	.	0.3
	Waiting on the day of treatment	.	62	62	62	.	2.0
	Column totals (2013)	.	58	282	340	0.21	11.1
Total			354	778	1132	0.46	12.2

Table 19 - Subcategories of comments on chemotherapy care by period of observation.

Patients' Comments in this area reflected significant appreciation for the way staff had dealt with them during what were often framed as difficult periods of treatment. Such comments persisted even where other problems were encountered, such as extended waits on the day for chemotherapy treatment.

Quality of information provided during chemotherapy was the other area of comment relating to communication. Far fewer patients provided comments in this area, with a mixed-to-negative balance of comments across the periods of observation. Negative comments reflected experiences of inadequate information provision in relation to side effects, as well as issues in support for decision making with respect to treatment options.

> *I suffer from secondary bone cancer, recurring from breast cancer 17 years ago. I've been having hormone treatment for the last 18 months. Now my hospital doctor seems to think it's not doing its job. The other treatment is chemotherapy. It was explained to me that this could work or not. I was explained the side effects but the decision is left to me. I honestly don't know what to do so I rang Macmillan cancer support - to no avail. I was told there's no funding for support nurses. I feel very let down as I feel I need to speak to someone to help me and support me to make the right decision. In this day and age I think it's really bad you can't get any help and support to make a life changing decision. I feel very alone and let down*. (Female, aged 66-75 years, 2010 CPES)
>
> *Yes, explanation of side effects. I lost my hair nearly 3 years ago. I was told the `cold cap` would not work with the chemo I was being given. Had I known that I would be left bald I would have prepared myself, at least mentally & tried the `cold cap`*. (Female, aged 51-65 years, 2010 CPES)
>
> *Communication of a meaningful nature between patient, nurses and senior consultants is poor in the extreme. I was given no information regards important dos and don'ts prior to chemo commencing. This was because my treatment was farmed out to a ward as the chemo centre was full. Unfortunately the wards attention to communication was way behind the level adopted by the centre*. (Female, aged 51-65 years, 2013 CPES)

In terms of positive comments, these generally referred to the ability of specialist staff to deal with queries during treatment.

> *Whilst on chemotherapy (capactiabine) I was anxious about side effect on 2 occasions. I telephone ward and was given immediate advice and reassurance. The nurses giving me I.V herceptin were all very efficient and very pleasant. I am now on the healthcare at home I.V herception plan and very satisfied with the staff*. (Female, aged 76+ years, 2010 CPES)
>
> *Yes, every step of the way, I cannot speak highly enough from day one and every department they were wonderful. Especially Dr [name 1 removed] and [name 2 removed] (chemo nurse specialist) if I ever had a query [name 2 removed] was great, either on the end of a phone straight away or he'd ring back*. (Female, aged 66-75 years, 2011-12 CPES)
>
> *The hospital staff were brilliant. The staff on the chemotherapy ward cannot be faulted. If I have any concerns or problems at any time of day or night - we ring and they always help. I also feel cared about - they remember my name and always ask how I am*. (Female, aged 51-65 years, 2013 CPES)

Both positive and negative comments reflect the importance of staff availability to answer questions both prior to and during chemotherapy treatment, and in each case we see corresponding consequences for patient confidence.

3.13.3 Waiting on the day of chemotherapy treatment

Large numbers of those giving comments about chemotherapy made comments regarding waiting times on the day of treatment, all of which were negative. Common reasons attributed to these delays included inadequate staffing levels and delays in delivery of chemotherapy drugs from pharmacy.

> *Chemo drugs take a long time to come from Pharmacy when prescribed same day. I have been waiting 3 hours with drip inserted (at Chemo Day Unit)*. (Female, aged 66-75 years, 2010 CPES)
>
> *The waiting times before appointments are always over an hour and a half late, which is incredibly stressful in an over-full waiting room. Also the lack of nurses during chemotherapy means that not only are appointments delayed, but once being treated…* (Female, aged 66-75 years, 2010 CPES)
>
> *I am not sure how this could be improved due to the nature of having Chemotherapy but the days spent on the [name removed] Unit can be long and uncomfortable, waiting for blood results and your slot for having your Chemotherapy I have been there for 7 1/2 hrs. The nurses are always apologetic and endeavour to keep you informed of time scales but when you are feeling at your worst it can be exhausting - (need comfy chairs in waiting room!!)* (Female, aged 36-50 years, 2011-12 CPES)
>
> *Terrible waiting time to see oncologist, specialists, and prescriptions and to give blood 1-2 hours wait is normal. Also pharmacy doesn't always get chemo up to the chemo ward on time and the nurses have to chase causing further delay in treatment*. (Female, aged 66-75 years, 2011-12 CPES)
>
> *Delivery of chemo to unit from pharmacy is far too slow. I don't want to be in that room a minute longer than I need be. One occasion I waited 5 hours before I even got started on treatment. It's mental torture. I hate the smell, noises, listening to people talk about cancer. It reminds me why I'm there. Please, please speed it up. I would have expected more advice on diet and exercise and exercise anything to help keep cancer growth at bay perhaps? I wanted to feel empowered by something I could do to help myself*. (Female, aged 51-65 years, 2013 CPES)
>
> *I am attending chemotherapy unit every three weeks for continuing treatment. The staff are all very kind and caring. But the waiting times for treatment are extremely stressful as a 1'o clock appointment most times would be delayed for 2-3 hours before the actual treatment begins. It is not a good situation for a cancer patient to be in as stress levels get really bad because of the wait. I would like to be seen and have my treatment as near to my appointment time as possible. The delays are not acceptable and are a constant source of discussion with patients in the waiting room*. (Female, aged 66-75 years, 2013 CPES)

Delays in chemotherapy were reported as significant negative aspects of patient experiences, even in circumstances where staff were praised for the care given (this often occurred alongside perceptions of inadequate staffing levels). As the comments indicate, while an inconvenience for some patients, for others extended waiting for chemotherapy resulted in significant physical and/or psychological stresses. In some cases, these issues were compounded by poor experiences relating to treatment and waiting environments in the chemotherapy phase of the cancer journey.

3.13.4 Issues relating to chemotherapy environments

A smaller sub-set of patients commented on their experience of treatment and waiting environments during chemotherapy, all of which were negative. Although a range of issues were identified, a common theme related to overcrowded or ‘cramped’ conditions in waiting areas.

> *Cramped conditions in the chemotherapy unit over recent months. (Not enough space for either treatments or waiting for either treatments or to see a doctor*). (Female, aged 76+ years, 2010 CPES).
>
> *More nurses to do chemotherapy and a larger ward and waiting room as every seems to be crowded in a small space and there could be another room at a day hospital to help take pressure off the staff and less waiting time to see the doctors*. (Female, aged 51-65 years, 2010 CPES)
>
> *The chemotherapy unit is overcrowded with a lack of privacy. On several occasions I have been in the unit all day waiting for treatment when it should only take a couple of hours*. (Female, aged 76+ years, 2011-12 CPES)
>
> *Out-patients departments chemotherapy and blood transfusion areas extremely poor, over crowded uncomfortable, busy like a cattle market. An awful place to go when feeling unwell. Staff try hard to be nice but are used to the conditions. I really cannot face going back again*. (Female, aged 36-50 years, 2011-12 CPES)
>
> *More room needed in chemotherapy unit*. (Male, aged 66-75 years, 2013 CPES)
>
> *The ward I received my chemotherapy is cramped and not very nice. A bigger ward would be much better*. (Female, aged 51-65 years, 2013 CPES)

These difficulties exacerbated problems relating to waiting time, particularly for those with other physical health issues and for those who related existing stresses relating to the process of undergoing chemotherapy.

3.14 Radiotherapy

3.14.1 Overview

In total, 384 (4.2%) comments described experiences of chemotherapy across the three periods of observation (Table 20). Findings indicate a far higher proportion of positive comments compared with negative responses (i.e. an overall ratio of 0.36 : 1), with the ratio of negative-to-positive comments remaining broadly stable across all three periods. A broadly comparable ratio of negative to positive comments were provided by both WCPES respondents and patients with CUP across the three time-points (i.e. 0.42 : 1 vs. 0.5 : 1).

Year	Negative respondents (n)	Positive respondents (n)	Total respondents (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	28	102	129	0.27	4.3
2011-12	43	100	142	0.43	4.5
2013	32	81	113	0.39	3.7
Total	103	283	384	0.36	4.2

Table 20 - Breakdown of comments on radiotherapy by period of observation

The majority of comments were general (i.e. radiotherapy was praised as part of a general comment about all or a large part of the cancer journey). However, the comments also included responses relating to communication with radiotherapy staff and the speed of referrals to radiotherapy (Table 21).

3.14.2 Communication between patients and radiotherapy staff.

The majority of comments relating to communication were almost all positive where this concerned the manner in which patients were dealt with by staff. Comments here reflected experiences of receiving attentive and responsive care from radiotherapy staff.

> *The radiotherapy staff were lovely and helped put me at ease in a frightening situation. The whole thing was well organised and ran smoothly*. (Female, aged 66-75 years, 2010 CPES)
>
> *The radiotherapy treatment was out of this world. The staff and radiologists took the time to get to know you and always genuinely appeared to care if you had a good or bad day*. (Male, aged 51-65 years, 2010 CPES)
>
> *Although harassed/very busy, radiotherapy teams at all times try to make patients feel individuals. Kindness of staff in general*. (Female, aged 51-65 years, 2011-12 CPES)
>
> *The staff at the Radiotherapy Unit at the (Hospital name removed) were particularly kind and put me to my ease when I was nervous about the treatment. [Hospital name removed] is run very efficiently and the staff are kind and caring*. (Female, aged 66-75 years, 2011-12 CPES)
>
> *While having chemo and radiotherapy, I found the nurses in both departments very friendly and helpful, always ready with answers to any questions I may have had. Especially [name removed] in the radiotherapy department. She was always there with a sympathetic ear and hug when needed*. (Female, aged 51-65 years, 2013 CPES)

Year	Category description	Sub-category description	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	(General or miscellaneous)	.	14	57	71	0.25	2.3
	Speed of receiving radiotherapy appointments	.	5	3	8	1.67	0.3
	Communication between patients and staff	Quality of information	7	10	17	0.70	0.5
		Manner of staff	2	32	34	0.06	1.1
	Column totals (2010)	.	28	102	129	0.27	4.3
2011-12	(General or miscellaneous)	.	35	81	116	0.04	3.8
	Speed of receiving radiotherapy appointments	.	0	10	10	0.00	0.3
	Communication between patients and staff	Quality of information	7	0	7	0.00	0.2
		Manner of staff	1	9	10	0.00	0.3
	Column totals (2011-12)	.	43	100	142	0.43	4.5
2013	(General or miscellaneous)	.	12	50	62	0.02	2.0
	Speed of receiving radiotherapy appointments	.	4	4	8	0.00	0.3
	Communication between patients and staff	Quality of information	13	2	15	0.00	0.5
		Manner of staff	3	25	28	0.01	0.9
	Column totals (2013)	.	32	81	113	0.39	3.7

Table 21 - Subcategories of comments on radiotherapy by period of observation.

> *The radiotherapists at [Hospital name removed] are wonderful, caring and compassionate. The specialist nurses are very caring and supportive*. (Female, aged 76+ years, 2013 CPES)

Comments of this type convey experiences of reassurance and confidence in the care given by radiotherapy staff. The majority of comments in this section were negative in 2011-12 and 2013, following a reversal of trend in 2010. The majority of negative responses referred to a perceived lack of information regarding the potential side effects of radiotherapy.

> *I felt more could have been explained about the effects of radiotherapy treatment as I had quite severe side effects which would have been easier to cope with had I been forewarned about them*. (Female, aged 66-75 years, 2010 CPES)

> *I would like to not have been given lots of information about radiotherapy and side effects and possible need for further help e.g. tube feeding at that first consultation. Reading all of that at alone at home still recovering from neck [word unreadable] was very upsetting and in fact I worried about possible scenarios all the way through my treatment. Individual patients should be offered time to look at and discuss this with nurse as well as provided with written information*. (Female, aged 51-65 years, 2011-12 CPES)

> *Would have preferred more info about after effects of the radiotherapy*. (Male, aged 76+ years, 2013 CPES)

Negative comments here reveal some of the additional stresses caused by unexpected reactions to radiotherapy. Conversely in the positive comments, we observe equal and opposite experiences in relation to experiences of good information provision.

> *Chemotherapy staff and radiotherapy staff all very knowledgeable in their field - very approachable and helpful with all aspects of care and treatments*. (Female, aged 51-65 years, 2010 CPES)

> *The consultant radiography (oncologist) who [word unreadable] the radiotherapy treatment plan was also good at explaining the treatment before and at follow up consultation 1 month after end of 4 week course. The treatment "technicians" were good ([word unreadable]) as were nurses regarding diet etc*. (Male, aged 66-75 years, 2013 CPES)

Once again, timely and accurate information provision went hand-in-hand with positive experiences of radiotherapy treatment, and expressions of confidence in the treatment received.

3.15 Surgery

3.15.1 Overview

In total, 1700 (18.4%) comments described experiences of surgery (Table 22). Findings indicate a higher proportion of positive comments compared to negative comments, with the ratio of negative to positive comments remaining broadly stable across the three periods of observation. A similar ratio of negative to positive comments were provided by both WCPES respondents and patients with CUP across the three time-points (i.e. 0.46 : 1 vs. 0.46 : 1).

Year	Negative respondents (n)	Positive respondents (n)	Total respondents (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	175	380	555	0.46	18.3
2011-12	195	430	625	0.45	19.8
2013	170	350	520	0.48	17.0
Total	540	1160	1700	0.46	18.4

Table 22 - Breakdown of comments on surgery by period of observation

Comments describing experiences of surgery were broken down under four subcategories, including general or miscellaneous: communication between patients and surgical staff; the speed with which surgery was arranged; and general surgical care (Table 23). In all three subcategories, positive comments were prevalent over negative comments.

3.15.2 Communication between patients and surgical staff

Comments in this section included both the quality of information provided and the manner with which surgical staff interacted with patients and their families.

> *The surgeons are nice and explained everything they did during the operation*. (Female, 51-65 years, 2010 CPES).
>
> *I had met my surgeon before, she was fully briefed on my case, she gave me confidence about the procedure as well as telling me the risks. It helped me to prepare for my op and I was pleased that she was going to be the one looking after me*. (Female, 51-65 years, 2010 CPES).
>
> *My care and treatment by all staff at [hospital name removed] was outstanding. I was treated as an individual and with respect. My treatment was explained to me and what I was to expect. I felt safe and I trusted the doctors totally*. (Male, 51-65 years, 2010 CPES).
>
> *Information following operations to my relatives was very quick, and by the operation surgeon, which relieved much worry*. (Female, 66-75 years, 2011-12 CPES).
>
> *The breast cancer surgeons were very caring and explained everything and answered all my questions, their aftercare was excellent. Breast cancer nurse always available or rang me back with help*. (Female, 51-65 years, 2011-12 CPES).

Year	Category description	Sub-category description	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	(General or miscellaneous)	.	0	79	79	0	2.6
	Communication between patients and staff	Quality of information	38	47	85	0.86	2.8
		Manner of staff	43	56	99	0.75	3.3
	Speed of surgery		49	92	141	0.53	4.6
	General surgical care		45	106	151	0.41	4.9
	Column totals (2010)		175	380	555	0.46	18.2
2011-12	(General or miscellaneous)	.	0	90	90	0	2.8
	Communication between patients and staff (manner of staff)	Quality of information	52	74	126	0.70	4.0
		Manner of staff	38	52	90	0.73	2.9
	Speed of surgery		49	91	140	0.53	4.4
	General surgical care		56	123	179	0.46	5.7
	Column totals (2011-12)		195	430	625	0.45	19.0
2013	(General or miscellaneous)	.	0	55	55	0	1.8
	Communication between patients and staff	Quality of information	25	50	75	0.5	2.5
		Manner of staff	40	60	100	0.67	3.3
	Speed of surgery	.	60	85	145	0.70	4.7
	General surgical care		45	100	145	0.45	4.7
	Column totals (2013)	.	170	350	520	0.48	17.0
Total			540	1045	1585	0.47	17.2

Table 23 - Subcategories of comments on surgery by period of observation.

Negative comments reported instances where surgical staff had been rude, brusque and inconsiderate.

> *Post-operative bedside visits could be extremely intimidating at time being surrounded by doctors; surgeons can make a patient feel extremely vulnerable*. (Female, 51-65 years, 2010 CPES).
>
> *To have a major operation and then to be told straight after that the melanoma has spread elsewhere is not good news and it was delivered badly/bluntly by the x-ray consultant*. (Male, 66-75 years, 2011-12 CPES).
>
> *My time on the ward after surgery was quite upsetting at times. Some of the ward staff need to learn some basic "people skills". The day I was discharged which was surgery plus 5 days didn't have a clue what was happening. The ward quite dirty*. (Female, 51-65 years, 2013 CPES).

There were also reports where explanations should have been more sensitively provided and information could have been more comprehensive. For example, some patients were insufficiently prepared for the side-effects of treatment, including pain. Some patients also reported having difficulty in understanding surgical staff from overseas, due to poor English skills and heavy accents.

> *I felt there could be more information/ instruction on post op care, in particular: massage and treatment of scar tissue; checking of lymph glands; monitoring for other melanoma*. (Female, 51-65 years, 2010 CPES).
>
> *More sensitive explanations re operation. In February 2009 – foreign doctor whose English was not good gave me info on possible outcome of surgery (15 min before going into theatre) which included possible paralysis with no quality of life – frightening when already nervous and about to be wheeled into theatre! Not handled well at all*. (Female, 51-65 years, 2010 CPES).
>
> *On my first visit to the hospital I was seen by a foreign surgeon whilst he was a very good doctor I am sure I couldn't understand what he was saying to me due to his poor English speech. When he asked if I had any questions I said no because it was really hard work to sit and listen to him. On leaving his surgery I asked the breast care nurse what he had said to me, she told me whilst standing in the corridor, I was not asked into a side room for privacy*. (Female, 36-50 years, 2010 CPES).
>
> *After one operation, the computer system was showing in theatre, even though I was in recovery. This led to some distress to my family who were told the operation was only a couple of hours and, after six hours, I was still shown in theatre*. (Female, 51-65 years, 2011-12 CPES).
>
> *Was not really prepared for the pain side of things. Especially living on my own. Also, was not warned about side effects of pain relief etc. after operation*. (Male, 51-65 years, 2011-12 CPES).

> *I could have had a fuller explanation before my back surgery about exactly what was going to be done. For example I did not know before my surgery that a rib was going to be removed*. (Male, 51-65 years, 2013 CPES).

A few patients reported there could sometimes be a lack of communication between surgical staff on the wards, and occasionally contradictory explanations were provided. These interactions did not engender much trust.

> *I felt that the first operation was done by a surgeon that had to ask me what he was going to be doing to me. Which I felt was a bit daunting - as I was very nervous and couldn`t think straight. I had never met this gentleman before, the experience was not very nice*. (Female, 66-75 years, 2011-12 CPES).

> *Some surgical staff directly contradicted diagnosis and treatment of oncologists. Quite distrusting for patient!* (Male, 51-65 years, 2013 CPES).

> *Communication of doctors on the wards. Last stay in hospital for 8 days and saw approx. 6 different doctors. All asked same questions - was told by 1 that I'd have to have an operation but by other I was told no I wouldn't. For 5 days it was very confusing and nobody knew what was happening. I was told nil by mouth then told I could eat then asked why was I eating as I was NBM. Doctors and nurses should communicate about each patient prior to arriving at the bedside*. (Female, 51-65 years, 2013 CPES).

3.15.3 Speed with which surgery was arranged

A majority of patients who described how long they waited for their surgery were happy with the time it took to be arranged.

> *From the time I was diagnosed with Prostate Cancer to having surgery was indeed very quick (less than 3 months), and the care and attention by all from the consultant surgeon to the nurses was excellent*. (Male, 66-75 years, 2010 CPES).

> *I felt totally at ease with everybody that treated me and felt they were all very caring and pleased how quickly I had my operation and treatment*. (Female, 66-75 years, 2011-12 CPES).

> *All was very good. When Dr [name removed] took charge he got to the bottom of my problem and went quickly to an operation*. (Male, 51-65 years, 2011-12 CPES).

> *Everyone involved in my care has been brilliant. My surgeon ensured that I had my operation in [hospital name removed] and fitted me into his already full list. This made me feel so much better*. (Female, 51-65 years, 2011-12 CPES).

> *To date, I have received excellent service from our NHS cancer care. After my first diagnosis in Feb 2006, I had my operation(s) at the end of March and back home in April. I am so thankful and grateful for the NHS looking after me*. (Female, 51-65 years, 2013 CPES).

> *Brief waiting time for operation and good follow up*. (Male, 51-65 years, 2013 CPES).

However, there were a number of patients who had their surgery delayed for one reason or another, and it sometimes required them or their families to be proactive in ensuring timely operation dates were arranged.

> *My operation was cancelled several times due to no beds. This was very stressful at a time when you don't need it*. (Female, 36-50 years, 2010 CPES).

> *My only observation was that there could have been better communication between chemotherapy at [Hospital 1 name removed] and timing for the operation at [Hospital 2 name removed] (liver resection). I feel that my name should have gone on an operating theatre list as soon as the chemotherapy had been completed. The wait between end of chemotherapy and the operation seemed unnecessarily long*. (Male, 51-65 years, 2011-12 CPES).

> *When I visited the outpatient clinics the doctors were aware of the final date of my chemo but instead of pencilling me in for the operation they left it until two weeks afterwards which meant a long gap between chemo and operation*. (Male, 51-65 years, 2011-12 CPES).

> *There was not enough care and attention paid to getting times of operations correct, as my first operation was cancelled on the day due to admin error, and the second operation was confusing from the letters received over dates and times*. (Female, 51-65 years, 2013 CPES).

> *I had to push to get appointments and a date for surgery at [detail removed] within the recommended time even though their performance was on the Dept. of Health website as 99% achievement of target for 31 days decision to treat to treatment*. (Female, 51-65 years, 2013 CPES).

> *My operation was delayed while I was in great pain. It took my husband complaining to staff to get something done*. (Male, 66-75 years, 2013 CPES).

3.15.4 General surgical care

The majority of patients who provided comments in this subcategory were positive about the surgical care they received. Individual members of staff were sometimes identified that had made a particularly positive impact upon the care of patients.

> *I had excellent hospital cancer care for my liver operation*. (Male, 51-65 years, 2010 CPES).

> *I cannot praise my surgeon, specialist nurses, the operating teams, ward staff and clinic staff, as well as my chemotherapy specialists, highly enough. This year I was re-admitted as a day care patient to have suspicious scar tissue removed - again successfully, and received superb care attention*. (Female, 51-65 years, 2010 CPES).

> *My circumstances were unusual in that I entered [hospital name removed] as a neurology patient and discovered I had stage 1V lung cancer and multiple brain metastasis. The team on the ward were outstanding and my care was second to none. It feels wrong to single anyone out, but Dr [name removed] is a gifted and sensitive doctor who gave me the utmost confidence in her medical judgement. Everyone worked hard to get the tests I needed as*

> *quickly as possible and I am very grateful for the exceptional and excellent care I received from everyone.* (Female, 51-65 years, 2010 CPES).
>
> *I was involved in an advanced recovery plan. This involved a written plan of expectations on a daily basis, with tick boxes to record action taken. Very good. I was out of hospital following liver resection in 3 days*. (Female, 51-65 years, 2011-12 CPES).
>
> *The operation itself was extremely good, no problem healing or with infections. If I had to have another like op, I would have every confidence in the Stanmore*. (Female, 51-65 years, 2013 CPES).

However, some patients reported their general surgical care had been less than optimal, either because staff were inefficient or that their attitudes were unsympathetic, mistakes were made during operations, or wards were understaffed.

> *Admission procedure/allocation of initial bed space extremely poor, 7 hr wait in hospitality lounge to be admitted for me. Hospitality suite poor and staff have poor attitude to patients. Long wait for medicines and discharge (example - 9 hrs of one patient observed. Nursing staff on men surgical, poor at night and very poor on weekend nights (no interest or compassion in patients)*. (Male, 51-65 years, 2010 CPES).
>
> *Medicines and pain relief were not given out when needed, only at set times. You really had to beg for pain relief. Dressings with an open wound that the dressing was taken off of for the registrar to look at a very considerable open wound at [time removed] in the morning, was not dressed again until [time removed] in the afternoon, so I laid on my back for [time removed], couldn`t drink go to the toilet or eat lunch. The cut was from my waist to just above my private area, was so deep he could actually place his hand inside the wound (the wound was open because of infection, and the stitches had been removed and the wound made deeper, it had a pump attached to take away fluids). When the special wound nurses came back to redress the wound I was told that all four nurses accompanied the surgeon throughout his rounds (several wards) before wounds were redressed. So I lay [time removed] with a blue paper cloth over me. Not good enough. Surely one nurse left to redress wounds would be better, and less chance of infection*. (Female, 51-65 years, 2011-12 CPES).
>
> *A careless operation performed by [name removed] at [Hospital name removed] on [date removed] when instrumentation was inserted in neck. Out of the 8 screws required 2 were not tightened properly and 6 weeks later had fallen out causing considerable pain. This required a second operation performed by [name removed] on [date removed]. Any further information can be obtained from PALS who hold a CD of the complaints meeting we had with them on [date removed]*. (Female, 66-75 years, 2013 CPES).
>
> *The hospital wards are understaffed and very noisy. Not very good for recovery from a major operation*. (Female, 51-65 years, 2013 CPES).

Some patients reported that they felt their hospital discharges were too soon following their operations.

> *I thought I was rushed a bit about going home after [number removed] days after the operation*. (Female, 51-65 years, 2011-12 CPES).
>
> *On the day of discharge from hospital it was all very rushed because the bed was needed. I had just had a major operation and was only in hospital two nights. I thought it was too soon to be discharged. Two nurses came to the bed packed all my things up in 5 seconds, flat and rushed me. I was getting flustered one was packing my case and one was changing my dressing all at 100 miles an hour. I was then hurtled in a waiting room where I had to wait for my daughter to pick me up. I was not even told I was being discharged until the nurse came to pack my things*. (Female, 51-65 years, 2013 CPES).
>
> *I found the day surgery for mastectomy meant I left the hospital with hardly the strength to walk from the hospital to the nearest place a car could be brought. I would have felt happier to know I had one night in hospital and could have just relaxed and slept*. (Female, 51-65 years, 2013 CPES).

Overall, however, comments by patients with CUP reflected predominantly positive experiences.

3.16 Palliative care

In total 135 (<0.01%) comments described experiences of palliative care across three periods of observation (Table 24). Findings indicate a far higher proportion of positive comments compared with negative responses, with the ratio of negative-to-positive comments remaining broadly stable across the three periods of observation. Comparable findings are not available from the WCPES data for this area.

Year	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	4	40	44	0.10	1.4
2011-12	6	43	49	0.14	1.6
2013	2	40	41	0.05	1.3
Total	12	123	135	0.09	<0.1

Table 24 - Breakdown of comments on palliative care by period of observation.

In terms of detail, the positive comments reflected high levels of satisfaction with palliative care in general. In some cases this was contrasted with less positive experiences of previous care, and/or anxieties around being discharged from the care of their previous teams.

> *The palliative care team were and are continuing to be excellent. The palliative care team provide an thorough & exceptional service that the hospital should be proud. It is a shame that this is not matched in all aspects of cancer care especially with C.U.P patients. We seem to fall through the net!* (Female, aged 36-50 years, 2010 CPES).
>
> *The whole experience was dreadful until we got to the hospice where the care was second to none*. (Female, aged 66-75 years, 2010 CPES)
>
> *I have been in pain for over 5 years. The doctor at chemotherapy saw how much pain I was in and they made arrangements for me to go in [name removed] Hospice last week. I am a lot better now but not 100%*. (Female, aged 66-75 years, CPES 2011-12)
>
> *All the staff at [name removed] Hospital, especially the consultants in the palliative cure/pain clinic who never rush an always make time to talk and explain treatment, also follow up the phone call when they say will consultants secretaries are also very helpful*. (Male, aged 76+ years, CPES 2011-12)
>
> *The treatment that [name removed] received on returning home for palliative care was excellent. All the agencies involved were very professional. Her family were most impressed by the care provided. We will be forever grateful for the caring treatment she received during her last days. [name removed] passed away at home with her family around her on [date removed]. (Husband*). *(Female, aged 51-65, CPES 2013)*
>
> *The best thing that happened was my referral to our local hospice for palliative care. They seem to have brought all the different people to see together, as one team. They also offer me excellent emotional support and treatments in their day therapy unit*. (Female, aged 66-75 years, CPES 2013).

In terms of negative comments, these referred to coordination between palliative care and other secondary care services, rather than the services per se.

> *In the transition from end of hormone treatment/chemotherapy to palliative care there were minor hiccups in co-ordination, especially with respect to prescriptions as between oncologist, GP, palliative care specialist and myself GP seemed to depend on me for updates*. (Male, aged 66-75 years, 2010 CPES)
>
> *When I saw the specialist the nurse gave me a book about secondary cancer but was not told I was palliative care therefore incurable. My daughter who was with me said `mum do you realise you`re in palliative care?` and I said `what, like dad?`. That was the one thing which upset me as I could have read that on the bus on my own going home. This was the last time at the hospital not the first, that was my only complaint. All other aspects and treatment were excellent*. (Female, aged 66-75 years, 2011-12 CPES)
>
> *Communication with palliative care via the GP as this was very slow to be put in place. Once in place, everything moved very quickly for the appropriate care. // My father died in [date removed] but I decided to fill this in if it would be helpful*. (Male, aged 76+ years, 2013 CPES)

Overall, however, comments by patients with CUP reported predominantly positive experiences of palliative care services.

3.17 Post-treatment care

3.17.1 Overview

In total, 186 (2.0%) comments described experiences of care in the post-treatment phase (Table 25). Findings indicate a slightly higher proportion of negative comments compared with positive responses, which remained consistent across the three periods of observation. The ratio of negative to positive comments was comparable with responses to the WCPES (i.e. 2.01 : 1 vs. 2.05 : 1). However, there was a lower percentage of patients with CUP who provided comments about post-treatment care compared with respondents to the WCPES (i.e. 2.01% vs. 6%).

Year	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset Coverage (%)
2010	35	26	61	1.35	2.0
2011-12	33	22	55	1.50	1.7
2013	38	32	70	1.19	2.3
Total	106	80	186	1.32	2.0

Table 25 - Breakdown of comments on aftercare by period of observation.

Most comments were general, either reflecting a lack of aftercare support, or providing positive examples of care in this phase of the cancer journey. The following are examples of negative comments.

> *Not enough information about aftercare of patient*. (Female, aged 66-75 years, 2010 CPES)
>
> *Notes to accompany every meeting. More follow up by hospital to see how we are coping. Information about my prognosis and support to come to terms with it. Information on what benefits I could apply for and in what order. Follow up more. Don't just give me a leaflet or printout but explain and call me a few days later to make sure all is OK and if any questions. I was told by a nurse at [hospital name removed] that I would be back to normal straight away after my surgery - 3 months on and I still can't walk or write properly*. (Female, aged 36-50 years, 2011-12 CPES)
>
> *As for the surgeon and doctors, they have done their best. But aftercare are non-existent. The procedure of dealing with the condition is terrible because not knowing what to do*. (Female, aged 51-65 years, 2013 CPES)

These comments convey a sense of anxiety on the part of patients relating to uncertainties in the post-treatment phase. Specifically, this appears to relate primarily to fear of recurrence and what steps would be taken to monitor this, as well as information and support for dealing with effects of cancer treatment.

In the positive comments, once again the consequences of good and timely aftercare provision provide a contrast with the negative comments.

> *The latest operation was fluid cancer surgery. The treatment was successfully removed and I am given follow up calls in case anything of cancer should arise*. (Female, aged 76+ years, 2010 CPES)
>
> *The specialist breast cancer care nurses were very supportive and were available to answer questions by phone and give me advice. They have remained so through the follow up care I receive from my consultant and his team*. (Female, aged 66-75 years, 2011-12 CPES)
>
> *I don't always need to see my consultant at my follow-up visits, but if I ask a question the junior doctor cannot answer they always go and find the answer or ask the consultant to come and talk to me*. (Female, aged 51-65 years, 2013 CPES)

These comments indicate the reassurance provided by timely information provision and the availability of staff to answer questions and address concerns. This goes beyond the presence of appropriate follow-up investigations to encompass other aspects of post-treatment experiences, underscoring the holistic nature in which positive experiences of aftercare are framed by patients.

3.18 Emotional, social and psychological needs.

3.18.1 Overview

In total 148 (1.6%) comments described emotional, social and psychological needs across the three periods of observation and the services available to address them (Table 26). Findings indicate a slightly higher proportion of negative comments compared with positive responses, with the ratio of negative-to-positive approximately even in 2011-12, but much higher for 2010 (i.e. 2.56 : 1) and 2013 (2.29 : 1). Overall, the ratio of negative to positive comments was comparable to responses from the WCPES (i.e. 1.87 : 1 vs. 2.19 : 1).

Year	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	46	18	64	2.56	2.1
2011-12	24	23	47	1.04	1.5
2013	39	17	49	2.29	1.3
Total	109	58	167	1.87	1.8

Table 26 - Breakdown of comments on emotional, social and psychological needs by period of observation.

3.18.2 Content of comments

Both negative and positive comments were general, reflecting a wide variety of experiences and settings in which emotional, social and/or psychological needs were present. In terms of negative comments, these often reflected calls for better information on sources of support, and/or improved attentiveness of staff to these needs.

> *The clinical nurse specialist was kind and sweet but not really on my wave length. When I was in the most frightening part of the tests, not knowing if the cancer was everywhere, I did not like watching some of the nurses in the scan room areas laughing and joking around. When you are in that position, thinking your life might end, you are very sensitive to such things I thought it was a bit insensitive. It made me realise they had no idea what I was feeling - the main nurse who showed me to my room was not like this at all, he was very understanding and considerate*. (Female, aged 26-35, 2010 CPES)
>
> *More could be done to help the patient at home. A leaflet I wrote to help people cope after their diagnosis could be given to everyone receiving that life changing news. Often practice helpful tips and information sites give support when away from the hospital. These leaflets and others are available from the 'help centre' at the oncology hospital. Talking to patients I've found few actually go in to find out information as often they don't know what to look for*. (Female, aged 51-65, 2010 CPES)
>
> *The registrar I saw on a few occasions gave me a rather different set of answers about the future options available to me than my oncologist consultant. The registrar did not appreciate the damage to my emotional well-being of his words. I no longer trust this registrar because his opinions were not aligned with those of my consultant, whom I trust completely*. (Female, aged 36-50 years, 2011-12 CPES)

> *Also counsellors I feel the minute you are told you have cancer you should be able to see a counsellor. People take the news in different ways. Some are strong and get on with life others crumble and hide*. (Female, aged 36-50 years, 2011-12 CPES)
>
> *I could have done with more support on the psychotherapy side, soon after diagnosis in 2009/10. I did request some, and have been given support, last year (2012). However, that was my specific request and feel it should have been offered sooner. It was very helpful, particularly since my diagnosis is not all that optimistic!* (Male, aged 51-65 years, 2013 CPES)
>
> *I have found it extremely difficult coping with cancer and an emergency operation for a perforated bowel (at the same time) with a colostomy performed. I feel that I should have had more emotional support*. (Female, 51-65 years, 2010 CPES).

The variety of comments appears indicative of the wide range of different needs present in the set of patients who provided comments on emotional, social and psychological issues. They reveal a broad category of outstanding needs that encompass both interactions between staff and patients in care situations, as well as information and support for ongoing needs during and following treatment. In so doing, they also highlight the impact that unmet emotional, social and psychological needs can have on patients during and following treatment.

In the positive comments, we see again equal and opposite reflections of negative responses, with patients praising the manner of staff and access to specialist support services.

> *All the staff in the hospital i.e. doctors, nurses, pharmacist, radiographers and health care assistant were pleasant and caring. They treated me as an individual and always ready to listen to me and allay my fears*. (Female, aged 76+, 2010 CPES)
>
> *Yes, my surgeon Mr [name removed] was and is fantastic. [name removed] - skin cancer nurse specialist is also brilliant, particularly with emotional support and always has 'time' for you. Mr [name removed] who informed me of the metastatic diagnosis also excellent and sensitive*. (Female, aged 51-65 years, 2010 CPES)
>
> *The cancer specialist nurses were a great help as you could phone them with any questions so as to put your mind at rest. Also, the dedication of the nurses looking after me. At times, I was very upset but they took time to care for me*. (Male, aged 51-65 years, 2011-12 CPES)
>
> *The contact between the clinical nurse specialist and the various agencies available to help e.g Macmillan and hospice services and counselling, all of which have proved invaluable*. (Female, aged 66-75 years, 2011-12 CPES)
>
> *My consultant and chemotherapy nurses are very caring and professional. They give a lot of support emotionally and physically. I get very good care under this health authority*. (Female, aged 36-50 years, 2013 CPES)
>
> *Excellent care and consideration given by all staff, with time given to listen to any fears or concerns*. (Male, aged 66-75 years, 2013 CPES)

In contrast to the negative comments, those who expressed satisfaction in meeting their emotional, social and psychological needs linked this to more general expressions of confidence in the overall care given to them.

3.19 Financial concerns

3.19.1 Overview

In total, 237 patients with CUP (2.6%) provided comments in relation to issues concerning finances across the three periods of observation (Table 27). Findings indicate a far higher proportion of negative comments compared with positive responses (i.e. an overall ratio of 12.16 : 1) with the ratio of negative-to-positive comments remaining broadly stable across all three periods. Comparing data with those from the WCPES, across all periods of observation the ratio of negative to positive comments was comparable for patients with CUP and those who completed the WCPES (i.e. 12.16 : 1 vs. 11.7 : 1). A greater percentage of total patients with CUP gave comments about finances compared with WCPES FT respondents (i.e. 2.6% vs. <1%).

Year	Category description	Negative comments (n)	Positive comments (n)	Total comments (n)	Negative to positive ratio (n : 1)	Dataset coverage (%)
2010	Miscellaneous	27	4	31	6.75	1.0
	Parking Costs	35	1	36	35.00	1.2
	Column totals	62	5	67	12.40	2.2
2011-12	Miscellaneous	56	5	61	11.20	1.9
	Parking Costs	26	1	27	26.00	0.9
	Column totals	82	6	88	13.67	2.8
2013	Miscellaneous	48	6	54	8.00	1.8
	Parking Costs	27	1	28	27.00	0.9
	Column totals	75	7	82	10.71	2.7
Total		219	18	237	12.16	2.6

Table 27 - Breakdown of comments on financial concerns by period of observation.

Many comments were of a general or miscellaneous nature, reflecting calls for more information and/or assistance with costs associated with cancer treatment. In particular, some patients called for more proactive provision of such information for cancer patients.

> *To be advised about all forms of support, financial and otherwise and not have to wait until you only have six months to live*. (Male, aged 76+, 2010 CPES)
>
> *I am currently a housewife and I am relying on my husband`s income to support our family (2 children). We suffered financial losses through treatment etc. and we had no support during that period (1 year).* (Female, aged 36-50 years, 2011-12 CPES)
>
> *I would have liked a little more support about financial aspects rather than worrying and finding out for myself, as I said I was in shock*. (Female, aged 51-65 years, 2013 CPES)

A smaller number of positive comments were also received (n = 18 overall) which praised the advice and support received in relation to financial costs associated with the cancer journey.

Comments associated with parking costs

Many comments in this category specifically described parking costs linked to cancer treatment. In all periods of observation, all but one of these comments was negative.

> *With great respect to clearly very busy doctors and staff, it is very distressing to wait well over an hour, sometimes two hours in packed waiting rooms. A side effect of this is the high cost of parking, especially for retired people/pensioners, who are occupying parking spaces needed for more urgent cases. A knock on effect is that one parks in streets adjacent to the hospital, putting too much money in the meter and having to walk back to the car in inclement weather, to feed the meter*. (Female, aged 66-75 years, 2010 CPES)
>
> *Parking is expensive and difficult, even though cancer patients do have some concessions, the amount of spaces is minimal so you are forced to try and park in the main car park which can cost up to six pounds a visit.* (Male, aged 51-65 years, 2011-12 CPES)
>
> *Parking at the oncology & haematology centre at [name removed] Hospital is hit & miss and if no space are available then you must go into one of the pay parks. A parking disc for the car should be issued allowing free parking in all the pay parks*. (Male, 66-75 years, 2013 CPES)

The very small number of positive parking comments reflected satisfaction with provision of parking permits for patients undergoing treatment, which helped to mediate some of the costs associated with the negative responses.

4. Discussion

Analysis of free-text comments within the CPES complements the formal closed questions by allowing respondents to indicate the issues most important to them and provides important insights of the experience of patients with CUP. There is little previous qualitative research on the experience of patients with CUP (Richardson et al. 2013; Boyland & Davis 2008). Nevertheless, the distress this group experience could be significantly greater than other groups of patients with advanced cancer at diagnosis because the primary cannot be identified (Boyland & Davis 2007). The place of uncertainty in the experience of illness (McCormack 2002) and specifically cancer (Shaha et al. 2008) is widely recognised. Mishel (1990) defines uncertainty as a state created when a person cannot adequately structure or categorise an event because of the lack of sufficient cues. Uncertainty influences cancer patients' experiences of illness extending to symptoms, diagnosis, treatment, relationships with caregivers and future planning. Uncertainty is a significant aspect of CUP, and involves an illness state where many of the uncertainties that accompany cancer are amplified and accompanied by a unique set of clinical ambiguities (Richardson et al 2013). Those with CUP may experience heightened levels of uncertainty due to the unpredictability of current and future symptoms, treatment options and undetermined life expectancy. No information exists concerning the effects of uncertainty about diagnosis and treatment on distress levels and psychosocial adjustment in this population.

CUP is also a challenging diagnosis for health professionals. Breaking bad news is a complex communication task and can affect a patient's comprehension, satisfaction with care and level of hopefulness. The task is all the more difficult when treating patients with CUP, due to the uncertain diagnosis and consequently the lack of a clear treatment plan or prognostic information (Ryan et al. 2010; Symons & James 2009). The Guideline issued by NICE in July 2010 acknowledged that patients with CUP were 'disadvantaged in many ways' and identified numerous difficulties regarding diagnosis and treatment. These ranged from lack of agreed definitions, uncertainty over appropriate diagnostic test and what constitutes optimum treatment, to lack of efficient care arrangements and inadequate support (NICE 2010). In response to these difficulties, the Guideline offered specific diagnostic and referral pathways and recommended the formation of specific teams to take responsibility for CUP patients.

The national CPES is an extensive, UK-wide programme of research on cancer patients' experience of care while undergoing inpatient or day-case treatment. The CPES has now been administered in England at four observation points (2010; 2011-12; 2013; 2014). The free-text data analysed for this report comprised comments provided by respondents with CUP from the first three of these surveys, for which data were available at the time.

General or miscellaneous comments were more numerous amongst positive comments, while negative comments tend to be richer and more specific. The latter often give greater information, therefore, concerning how services should be improved to ensure the treatment experiences of future patients are improved. The preceding sections have identified a number of themes from within the comments. Most of these are not new, but their prevalence in the data and their persistence amongst a large population of patients with cancer indicate they remain salient to this group. These data are longitudinal, but while there have been improvements in response to some closed questions over the three survey time-points, most of the ratios of positive to negative comments remained stable over these periods amongst free-text responses. This was the case both for themes where positive comments outweighed negative comments (i.e. ‘consultants’; ‘CNSs’; ‘radiotherapy’) as well as where negative comments were predominant (i.e. ‘GPs’; ‘aftercare’).

We have also been able to make comparisons between the proportions of comments from patients in this CUP dataset identified under each of the themes with findings from the Welsh national CPES (WCPES) data (2013), which comprised patients with any form of cancer diagnosis. It might be expected that findings for these two surveys would differ. The national Wales data incorporated all patients with a cancer diagnosis, while this study included only those within ICD codes 76-80. The method of analysis was also different, with WCPES comprehensively manually coded and the CUP data being mined for comments on specific themes. However, for most themes findings were broadly similar, although there were some notable differences: twice as many respondents with CUP provided comments relating to chemotherapy than Welsh national responses, and more CUP patients described investigations, which might indicate the greater treatment burden of this group. In contrast, the proportion of CUP respondents found to describe aftercare was only a third of that amongst the WCPES, possibly indicating that a higher proportion of CUP respondents were undergoing continued treatments when completing the survey.

The following section discusses issues related to identifying patients with CUP. The two subsequent sections discuss overarching themes that emerged from the data and cut across the categories of coded data. These cross-cutting themes have been organised under two sub-headings: coordination of care; and person-centred care.

4.1 Defining patients with CUP

Previous epidemiological studies have estimated between 3-5% of all new cancer diagnoses are CUP (Pavlidis 2007). However, CUP is an umbrella term and covers a wide range of clinical presentations and histological appearances where the primary remains unknown. There is also heterogeneity in terms of the definition of CUP (Brewster et al. 2014). The NICE Guidelines acknowledged some problems regarding definitions, in that the term CUP was often used in an inexact manner and frequently applied to individuals who had only received limited investigations. In an attempt to firm up the nomenclature applied to patients, the NICE Guideline developed a taxonomy (Appendix 2) to reflect different phases of investigation. However, as noted by Brewster et al. (2014), it is not always possible to make these distinctions in population-based cancer registry data because there is often limited information regarding the extent of diagnostic investigations.

As with Brewster et al (2014), this study analysed comments from CPES respondents registered under the tenth revision of the International Statistical Classification of Diseases and Related Problems (ICD-10) codes (WHO 2011): C77 (Secondary and unspecified malignant neoplasm of lymph nodes), C78 (Secondary malignant neoplasm of respiratory and digestive organs), C79 (Secondary malignant neoplasm of other and unspecified sites), and C80 (Malignant neoplasm, without specification of site). While this is how NICE in the UK defines CUP, this definition is not as broad as that used by the International Agency for Research on Cancer (IARC) (Cuardo et al. 2007). The IARC also include ICD-10 codes C26; C39; C48; and C76.

However, there are also issues with surveying patients with CUP in that many patients will eventually have their primary identified. When patients in this sample described their cancer, few did so in terms of ‘carcinoma of unknown primary’ or ‘CUP’. Many described themselves as having ‘secondary cancer’, or ‘rare cancer’, but it was also clear that many believed they had a known primary site, despite being identified under ICD codes covering CUP. Previous research had found that some patients with no diagnosed primary find it difficult to understand their condition or to describe it to others, and that a way of managing this was to talk about it in terms of the known secondary (Richardson et al. 2013). However, it is also likely that while many of these patients would have been coded under ICD codes covering CUP when identified as eligible for this survey, they may have subsequently received a primary diagnosis during the interval from being discharged from treatment and receiving the survey questionnaire. This interval may have been up to six months.

4.2 Coordination of care

Care coordination encompasses numerous aspects of health service provision including appropriate care that is timely and provided by a multidisciplinary team comprising medical, nursing and allied health professionals (Walsh et al. 2010). A lack of coordinated care can lead to fragmented care, patients getting ‘lost’ in the system and failing to access appropriate services, as well as more unplanned health utilisation (Walsh et al. 2010; Flessig et al. 2006).

Specialist referral and diagnoses

Many theories have sought to classify delays to treatment of cancer (Bairati et al 2006; Facione & Facione 2006; de Nooijer et al. 2001; Unger-Saldana & Infante-Casteneda 2011; Andersen et al 2010). ‘Provider delay’ commonly refers to delays in commencement of treatment once a patient has reported symptoms to a health care professional, normally their GP in the first instance. Reports of such provider delay was a strong theme within the free-text data, and included referrals to secondary care, diagnostic investigations and treatment. Any delay to diagnosis and treatment of cancer has the potential to impact negatively on patient outcomes (O’Rourke et al 2000). For patients who suspect they might have cancer and conscious of the risk of progression of the disease, delay also causes psychological distress, which has been shown to correlate positively with the length of that delay (Risberg et al 1996). Nevertheless, despite the NICE guidelines on patients suspected of cancer (NICE 2005), delays in referrals, investigations and diagnosis continue to occur.

Delays begin with GPs reportedly not taking symptoms presented by patients sufficiently seriously, with respondents in the CUP data sometimes reporting having consulted their GP many times over the course of months and even years for symptoms indicative of cancer without being referred for investigations or secondary referrals. Such delays early on in the treatment journeys of respondents contributed to the predominance of negative comments amongst those that commented upon experiences of interaction with their GP. The proportion of negative comments was greater amongst CUP comments than amongst comments within the Welsh national CPES.

Previous research has found that patients are often not satisfied with the time it took for the GP to identify their problem and for a diagnosis to be reached (Davidson et al 2005). Delays for investigations and referral are often caused through ‘misdiagnosis’ with GPs either treating patients symptomatically or relating symptoms to a health problem other than cancer, while for some cancers this could also be linked to inadequate patient examination, use of inappropriate tests or failing to follow-up negative or inconclusive test results (Macleod et al 2009). Previous studies have also found large variations in GP referral rates of patients with suspected cancer to specialist care

(O'Donnell 2000), with two-thirds of this variation remaining unexplained (Sullivan et al. 2005). Previous research with CPES data also identified wide variations (7.4% for breast cancer and 50.6% for multiple myeloma) between cancer types in the proportion of patients who had visited their GPs three or more times before hospital referral, but these tumour types did not include CUP (Lyratzopoulos et al. 2012).

The UK performs poorly compared with other advanced industrialised countries in the survival rates of patients with cancer. A recent study from the International Cancer Benchmarking Partnership (ICBP), a collaboration between 6 countries and 12 jurisdictions with similar primary care-led health services, investigated primary care physician (PCP) behaviour and systems that may contribute to the timeliness of investigating for cancer (Rose et al. 2015). The study demonstrated a correlation that suggests a relationship between the readiness of PCPs/GPs to investigate or refer for to secondary care for suspected cancer and cancer survival in each jurisdiction. The study also found significant variations between jurisdictions in access to diagnostic tests such as MRI and CTs (Rose et al. 2015). Our findings from patient comments would indicate that some of this delay may partly be addressed by GPs more often taking patients' concerns seriously and acting on them swiftly.

Communication between health agencies

The theme that perhaps stands out most from the data is the reported lack of communication between different health sectors (e.g. primary and secondary), different providers (e.g. trusts), and even different hospital departments and health professionals within the same trust. Around 15%-16% of comments described intra-agency communication over the three time-points with a relatively stable ratio of negative to positive comments (2.20:1 - 2.38:1). This suggests improvements had not taken place for this patient group between the years 2010-13. Moreover, the proportion of comments related to intra-agency communication was higher amongst patients with CUP than in the WCPES data (11.8%, n=554), but had a similar proportion of positive to negative comments. This suggests that this theme was more of a problem for patients with CUP than a general population of patients with any tumour type. Indeed, previous evidence suggests that patients with CUP are frequently passed between MDTs as clinicians 'chase the primary', in what has been described as 'MDT tennis' (Richardson et al. 2013). There was some limited evidence of MDT tennis in the data.

There were occasions when patients' notes were reported missing when needed at outpatient clinics, with important investigation results and information of previous consultations unavailable, and patients are too often not being sent outpatient clinic appointments. Within many of the other themes that describe either treatment (e.g. 'chemotherapy'; 'radiotherapy') or interactions with health professionals (e.g.; 'consultants'; 'GPs'), high proportions of negative comments reported instances of poor intra-agency communication. Respondents often associate this problem with increased anxiety and a feeling they must be vigilant and proactive to ensure they receive clinic appointments. Often they also felt the need to 'fill in the gaps' at consultations with health professionals, explaining the investigations and treatments they have undergone in the absence of clinical notes.

Patients with CUP will often be under the care of several consultant teams and different MDTs at any time (Richardson et al. 2013), meaning the opportunity for breakdowns in intra-agency communication is increased. For patients already facing the uncertainty of a CUP diagnosis, this added anxiety may have a greater impact. It is also possible that missing information will lead to duplication of investigations or even delay treatment. Within respondents' comments, incredulity is sometimes expressed that in this age of advanced informational technology, communication within and between hospitals rely upon paper notes that are so easily mislaid or misfiled and computer systems are frequently not updated. As one respondent noted, 'it can sometime take weeks for the results of scans to cross a corridor'. Poor communication between hospitals, departments and health professionals will inevitably impact upon coordination and continuity of care.

Investigations and treatment

Treatment for any tumour site can be complex, and given the wide range and numbers of health-care professionals involved, there exists an enormous potential for poor coordination and miscommunication. One study found that patients, who had been treated for cancer for less than a one year period, saw 28 doctors on average, and this figure does not include other health professionals involved in their care (Smith et al 1999). Treatment complexity can be expected to be greater for patients with advanced cancer or CUP, where the number and diversity of health professionals is often greater (Richardson et al 2013). Indeed, the ratio of negative to positive comments regarding diagnostic investigations in this dataset was 5 to 1, with concerns overwhelmingly being the time for investigations to be arranged and for results to be received and discussed. Such delays were strongly associated by patients with poorer prognosis and outcomes, and high levels of uncertainty and anxiety were reported.

Continuity of care

Poor communication and coordination of cancer care will also translate into a lack of continuity of care and transitional care, with care too often perceived to be provided in what some respondents' comments in the data described as 'silos' (Fennell et al 2010; Shine 2002). Continuity of care has been defined as one patient experiencing care over time as coherent and linked (Reid et al 2002), and has become one of the key policy themes in cancer care (DH 2008; Freeman & Hughes 2010). Continuity of care incorporates three components: informational, management and relational (Haggerty et al. 2003). Informational continuity links one provider to another and one healthcare event to another so that aspects of a patient's medical condition, preferences for treatments and the context of their illness are accounted for; management continuity is the delivery of health care by several providers in a complementary and timely manner through shared management plans that are consistent and flexible; relational continuity bridges past and current care while providing a link to future care, achieved through a core of consistent staff working together with the patients on their treatment plans (Nazarath et al. 2008).

Evidence indicates that higher experienced continuity of care amongst patients and their families is associated with lower future needs for supportive care and better psychological outcomes (King et al. 2008; NCCDSO 2007). Thus, if patients receive adequate preparation for what to expect with regards treatment side effects and self-management strategies, and then experience good continuity of care, their post-treatment needs may be reduced. Patients' comments support this claim with frequent references to both positive and negative experiences of care continuity across all stages of the cancer journey. In particular, concerns exist over transitions from primary to secondary care at the diagnostic stage, and then from secondary to primary care in the post-treatment phase. While these are generic concerns for all cancer patients, the added complexity of a CUP diagnosis may mean they become amplified (Richardson et al 2013).

Post treatment care

The CPES is administered to patients currently receiving treatment and therefore post-treatment experiences of care are unlikely to be the focus of many comments. Nevertheless, compared with the WCPES (2013) data that found 6% of respondents with any type of cancer providing comments describing their post-treatment care, only a third as many (2%) comments were identified under this theme amongst CUP respondents. This may be a result of the differing methods of analysis, but it may be attributed to a low survival rate for patients with CUP. Survival rates for patients with CUP are very poor, with one meta-analysis indicating a median survival of 4.5 months, with 1-year survival rate of 20% and 5-year survival rate of 4.7% (Greco & Pavlidis 2009).

Comments provided by patients with CUP often did not describe specific issues related to aftercare, other than to describe its lack. Comments conveyed a sense of anxiety on the part of respondents relating to uncertainties in the post-treatment phase, specifically a fear of recurrence and the effectiveness of services to monitor this, and information and support from health professionals to help them deal with the effects of cancer and its treatment. Previous research has found that patients with cancer often feel ‘cut adrift’ by the health system after the period of hospital treatment and are left feeling vulnerable and isolated (Armes et al 2009; Penny et al 2000). The transition from secondary to primary care can also mean patients need to adapt to the changed care setting, where they obtain prescriptions from different prescribers and sometimes find it difficult contacting appropriate health professionals for guidance (Coleman & Berenson 2004). A lack of clarity regarding the process of care was also identified as an issue for survivors post treatment, in part associated with less contact with services (Pollock et al, 2008). Evidence indicates that approximately 30% to 50% of cancer survivors have unmet needs, mainly for psychological support and coping with fear of recurrence (McIllmurray et al 2001; Boberg 2003; Hodgkinson et al 2003). Fear of recurrence is a generic concern for all cancer survivors, but for patients who have had a diagnosis of CUP it may have greater resonance, because if no primary has been diagnosed a recurrence could appear in any part of their body. Post-treatment needs may go unmet for months following treatment, with one study finding that the situation did not improve over a six month period for 60% of these patients with cancer (Armes et al 2009).

Coordination role of clinical nurse specialists (CNSs)

Fundamental to continuity of care are key workers, usually a CNS, who should be responsible for coordinating treatment and care during active treatment to ensure good communications between the healthcare team and the patient and their families, and to act as their point of contact (NICE 2004; Sullivan & Eliott 2007). Post-treatment this role should be transferred to GPs or their practice nurses. A full holistic assessment should be undertaken and a written plan of care developed. However, it appears that this is not occurring in many instances and very few patients’ comments referred to care plans or used the phrase ‘key worker’.

Many patients did refer to their CNS, and almost always described them as ensuring a more positive experience of care. Most of the negative comments in this category reported difficulties with being able to access or contact a CNS, with some patients not being allocated to a CNS. Specialist nurses play a key role in the coordination of care and provision of emotional support, information and supportive interventions and are central to improving the quality of nursing care (NHS Confederation 2010; NICE 2009; Lancet 2011). Access to a CNS allows a patient to develop a relationship with at least one key health professional who they can contact throughout their patient journey, ensuring that management and relationship continuity are mutually supportive reinforcing (Haggerty et al. 2003). However, significant variations across Trusts / Hospitals remain in patient access to specialist nurses (Trevatt & Leary 2010). Moreover, until adopted by a tumour specific MDT patients are sometimes not allocated a key worker/CNS. It was for this reason the NICE Guidelines (2010) recommended the establishment of specialised CUP teams within each NHS Trust that included a CNS. Comments from patients reporting limited access to a CNS often described uncoordinated and interrupted care, especially during the transition between secondary and primary care at the end of treatment. This finding indicates that there is still work to be done to implement and ensure consistency of care planning and continuity of care for this group of patients.

4.3 Person-centred care

While closely related to coordinated care, person-centred care also involves patients being treated with compassion and respect, health professionals and patients working together collaboratively, ensuring services are tailored to the needs of the individual, and where patients are able to participate in shared decision-making (Munthie et al. 2012).

Courteous and respectful treatment

Respondents frequently described the manner in which health professionals interacted with them, whether they conveyed a caring and attentive attitude that put patients at ease and generated confidence in their care, or whether they did not. A relatively large proportion of comments, both positive and negative, coded into themes regarding treatment types (e.g. chemotherapy; radiotherapy; surgery) and health professionals (e.g. nursing; GPs; consultants; CNSs) concerned the manner with which respondents were treated: whether, as many described, they were treated as ‘a person’ or as ‘a human being’ with respect and dignity, or as merely ‘a number’ or ‘set of symptoms’. Previous research has indicated the importance of the quality of interactions between health professionals and patients for much of the success of healthcare provision (Drew et al 2001), and being treated with courtesy and respect is one of the most important predictors for cancer patients’ perception of quality care (Sandoval et al 2005). It is also extremely important for ensuring patients have confidence in the rest of their care, especially when being informed of their diagnosis. As noted above, interacting with patients with CUP can be particularly challenging for health professionals due to the uncertain diagnosis and prognosis and difficulties selecting an optimum treatment plan (Ryan et al. 2010; Symons & James 2009).

These interactions occur across the treatment pathway, beginning in the GP surgery where patients’ concerns should be treated seriously, to being informed of their diagnosis in a sensitive manner with due concern for privacy and emotional support, and being treated with compassion and respect by medical, nursing and allied staff during treatment and post-treatment. Treating patients respectfully extends to keeping them informed when there are delays waiting for appointments, administrative staff returning phone calls when promised, and nurses ensuring as little noise at night as possible.

Good communication is not simply a one-directional relationship with health professionals providing information to patients, but a shared involvement (Quill et al. 1996; Emanuel & Emanuel 1992), and as many respondents indicated, it involves health professionals ‘listening’ to the concerns of patients. Recognition of a patient’s emotional needs and provision of reassurance by staff appeared to have a significant impact on the psychological wellbeing of respondents, and serves to emphasise the vital role that staff play throughout the patient journey in meeting emotional and social needs.

Patient information

Within many comment categories there were reports from patients that they had not received sufficient information from health professionals concerning treatment side-effects or advice on how to manage them. It seems clear that the more prepared individuals are for the problems they will face the less impact on their quality of life they will experience. Recent evidence supports this finding that patients with cancer want more information concerning effects of treatment and self-management strategies (Rutten et al 2005), but research also indicates that patients continue to receive what they perceive as sub-optimal levels of information and preparation (Ayanian et al 2010; Harrison et al 2012). The need for patients to be prepared for the potential impact of their diagnosis and treatment thus pervades the patient journey, and includes: available treatment options and the relative advantages and disadvantages for the individual; information concerning possible physical problems, how to manage them, when they might resolve, what to do if they don’t; emotional and psychological issues, such as fear of recurrence and other anxieties and how to find support should this be needed; managing financial and other practical problems, such as returning to work and benefit applications. Such support and guidance have previously been found to be important factors in patients’ satisfaction with their quality of care (Davidson et al 2005), but it requires sufficient and accessible specialist staff for its provision.

However, providing accurate and helpful information and preparing patients with CUP for their treatment journey is especially difficult given the uncertainty that pervades this diagnosis. The location of the primary tumour is the main reference point for prognostic information (Ryan et al. 2010), and treatment regimens may change several times during a patient’s journey (Richardson et al 2013). Many comments nevertheless attested to the importance of honesty for many patients, with health professionals being clear about the limits of the information they have themselves. Some patients reported thinking health professionals were ‘holding back’ on giving them information, which left them seeking a better understanding of their condition through use of the internet, and sometimes being ‘frightened’ by what they found. Beyond honesty, there is also an important role of clinical staff in advocating alternative sources of information, e.g. recommended websites or referrals to information centres, which may help bridge this issue.

There is a clear and consistent finding that information directly provided by health professionals during a consultation is the preferred source of information for patients. However, there is also evidence of a recognition of the workload of health professionals, the needs of other patients who are waiting and these factors influence whether further information is sought or requested (Bungay & Capello, 2009; Leydon, et al., 2000; Manning & Dickens, 2007). This finding is important when considering the utility of information provision interventions based in alternative approaches using video, print material or interactive electronic sources. Finally, as patients do not always want information at the same time or at the same level (Leydon et al 2000), patient preparation should be tailored to the needs of individuals.

Emotional, social and financial support needs

Relatively few comments from respondents with CUP were found that specifically described emotional, social and psychological needs explicitly. Where emotional and social issues were explicitly described, focus was primarily fears around diagnosis, treatment options and side effects, prognosis and uncertainty on the future. These issues were reported in relation to the stress and anxiety respondents' experienced, and indications that where services addressed them patients felt better able to cope with their condition. Support, guidance and sign-posting to counselling and support services; managing financial and other practical problems, such as returning to work and benefit applications have previously been found to be important factors in patients' satisfaction with their quality of care (Davidson et al 2005). Some participants gave positive comments relating to support services or reflected a desire for more information on sources of support. Nevertheless, the majority of respondents who described emotional needs indicated they were most effectively met in situ by staff involved in the main treatment phases of their cancer journey and often wished for improved communication skills and sensitivity from staff. This should not be interpreted as suggesting that other areas of support such as specialist counselling are less important (particularly as need for these services is indicated by negative comments), but rather serve to emphasise the vital role that staff in the main diagnostic and treatment phases of the cancer journey play in meeting emotional, social and psychological needs. Indeed, recent evidence shows that emotional support and support for the control of side effects are better in Trusts / Hospitals with more specialist nurses (Griffiths et al 2013).

Staffing issues

Within several themes there were comments that conveyed concerns over a lack of nursing staff and an associated lack of adequate care, although most such comments described nurses continuing to do their best. There were particular concerns around staffing on hospital wards at night and the sub-optimal skills and attitudes of some agency nursing staff. There has been much recent discussion regarding safe staffing levels in hospitals, particularly of nursing staff (RCN 2012). Growing international evidence indicates that lower ratios of nurses to patients are associated with both poorer outcomes for patients and greater job dissatisfaction for nursing staff (Needleman 2002; Aiken 2002a; 2002b; Rafferty et al 2007). It is probable that inadequate levels of staffing will also contribute to other problems experienced by patients with CUP, such as instances of uncoordinated care, lack of individualised care and waiting for treatment and pain control.

The role of the clinical nurse specialists (CNSs) in person-centred care

As with coordination of care, the role of the CNS with regards person-centred care was vital. Specialist nurses play a key role in the coordination of care and provision of emotional support, information and supportive interventions and are central to improving the quality of nursing care (NHS Confederation 2010; NICE 2009; Lancet 2011). Many patients described the importance of a CNS as a point of contact who provided information and explanations in terms they could understand, and were very important in helping patients maintain trust in their care.

4.4 Key messages from findings

Study findings clearly point to ways in which health professionals might better recognise, understand and address the needs of patients with CUP, and suggest ways in which care provided to patients with CUP could be improved. In particular, findings emphasise that patients with CUP need:

- Concerns about the symptoms they experience to be taken seriously by clinicians;
- To be treated with courtesy, sensitivity and respect, especially when being informed of diagnosis and results of investigations;
- Coordinated care to prevent delays in investigations and treatment;
- Continuity of care, managed by a single individual in whom they can have trust;
- To be kept informed of the reasons for and lengths of delays in appointments;
- Sufficient information about treatment options to make informed decisions about their care;
- To be adequately prepared for the physical and psychological effects of their condition and the side-effects of treatment;
- Financial advice and information concerning benefits, especially if self-employed;
- Adequate post-treatment care in the form of monitoring and addressing physical and emotional needs is essential to address the hiatus many patients experience when treatment ends; and,
- Access to a single CNS for the duration of their treatment journey.

Implementation of recommendations outlined in the NICE Guidelines for the management of CUP would help address many of these needs, although perhaps not all.

5. Limitations of the study

Data were volunteered by individuals and were not systematically recorded according to a structured list of topics of areas, and therefore are not necessarily representative. Recall and response bias may also be present. A high proportion of patients within the sample appeared to believe they had a known primary site, despite being identified under ICD codes covering CUP. Due to the methodology used for data analysis we were unable to report the overall total number of positive and negative comments. However, as our previous work with CPES free-text data has shown, a large proportion of positive comments are vague and very general, and provide little or no detail as to what aspect of their care patients were most content with. Focussing upon areas of specific interest therefore retrieves comments that have greater richness. As negative comments tend to be more informative there may appear to be a bias towards reporting these experiences.

6. Conclusion

This study reports the free-text responses of patients with CUP to the national CPES over the three points of observation for which data were available. As such, it is the largest study thus far of the experiences of care for this patient group and highlights the concerns experienced by patients with CUP and the aspects of care that they would like to see improved. It also supports the recommendation of the NICE Guideline on the management of patients with CUP that a specialist CUP team should be established in each NHS trust.

7. References

Aiken LH, Clarke SP, Sloane DM. (2002). Hospital staffing, organization, and quality of care: cross-national findings. Nursing Outlook 50(5): 187-94.

Aiken LH, Sermeus W, Van den Heede K, et al. (2012). Patient safety, satisfaction, and quality of hospital care: Cross sectional surveys of nurses and patients in 12 countries in Europe and the United States. BMJ 344. doi:10.1136/bmj.e1717.

Armes J, Crowe M, Colbourne L, et al. (2009). Patients' supportive care needs beyond the end of cancer treatment: A prospective, longitudinal survey. Journal of Clinical Oncology 27(36): 6172-79.

Ayanian JZ, Zaslavsky AM, Arora NK, et al. (2010). Patients' experiences with care for lung cancer and colorectal cancer: findings from the Cancer Care Outcomes Research and Surveillance Consortium. Journal of Clinical Oncology, 10.1200/JCO.2009.27.3268.

Boberg EW, Gustafson DH, Hawkins RP, et al. (2003). Assessing the unmet Information, support and care delivery needs of men with prostate cancer. Patient Education and Counselling 49(3): 233-42.

Boyland L, Davis C. (2008). Patients' experiences of carcinoma of unknown primary site: dealing with uncertainty. Palliative Medicine 22(2): 177-183.

Bracher M, Wagland R, Corner J. (2014). Exploration and analysis of free-text comments from the 2013 Wales Cancer Patient Experience Survey (WCPES). Cardiff, Wales, UK: Macmillan Cancer Support.

Brewster DH, Lang J, Bhatti LA, et al. (2014). Descriptive epidemiology of cancer of unknown primary site in Scotland, 1961–2010. Cancer Epidemiology 38: 227–234.

Bungay H, Capello R. (2009). ‘As long as doctors know what they are doing': trust or ambivalence about patient information among elderly men with prostate cancer. European Journal of Cancer Care, 18: 470-476.

Cancer Research UK (2015). Achieving World-Class Cancer Outcomes: A strategy for England 2015-2020. Report of the Independent Task Force. www.cancerresearchuk.org/about-us/cancer-taskforce

Coleman EA, Berenson RA. (2004). Lost in transition: Challenges and opportunities for improving the quality of transitional care. Annals of Internal Medicine 141(7): 533-36.

Curado MP, Edwards B, Shin HR, et al. (eds.)(2007). Cancer incidence in five continents, volume IX. IARC Scientific Publications No. 160. Lyon: International Agency for Research on Cancer.

Davidson R, Mills ME. (2005). Cancer patients’ satisfaction with communication, information and quality of care in a Uk region. European Journal of Cancer Care 14(1): 83-90.

Department of Health. (2000). The NHS cancer plan: A plan for investment, a plan for reform**.** London: Department of Health.

Department of Health. (2008). High quality care for all: NHS Next Stage Review final report. London: Department of Health Cm 7432.

Drew P, Chatwin J, Collins S. (2001). Conversation analysis: A method for research into interactions between patients and health-care professionals. Health Expectations 4(1): 58-70.

Emanuel EJ, Emanuel LL. (1992). Four models of the physician-patient relation-ship. Journal of American Medical Association 267:2221-6.

Freeman G, Hughes J. (2010). Continuity of care and the patient experience. Kings Fund, London.

Girgis A, Boyes A, Sanson-Fisher RW. (2000). Perceived needs of women diagnosed with breast cancer: rural versus urban location. Australian and New Zealand Journal of Public Health 24(2): 166-73.

Greco F, Pavlidis N. (2009). Treatment for patients with unknown primary carcinoma and unfavourable prognostic factors. Seminars in Oncology, 36(1), 65-74.

Griffiths P, Simon M, Richardson A, et al. (2013). Is a larger specialist nurse workforce in cancer care associated with better patient experience? Cross-sectional study. Journal of Health Services Research & Policy 18(1) suppl (April): 39-46.

Gysels M, Higginson IJ, Rajasekaran M. (2004). Improving spportive and palliative care for adults with cancer. Research Evidence Manual. London, England: National Institute of Clinical Excellence.

Haggerty JL, Reid RJ, Freeman GK, et al. (2003). Continuity of care: A multidisciplinary review. BMJ 327(7425): 1219.

Harrison SE, Watson EK, Ward AM et al. (2012). Cancer survivors' experiences of discharge from hospital follow-up. European Journal of Cancer Care 21(3): 390-97.

Hodgkinson K, Butow P, Hunt GE, et al. (2007). Breast cancer survivors’ supportive care needs 2–10 years after diagnosis. Supportive Care in Cancer 15(5): 515-23.

James N, Symons J. (2010). Chasing the primary. Cancer Nursing Practice 9:10.

King D, Jones L, Nazareth I. (2006). Concern and continuity in the care of cancer patients and their carers: A multi-method approach to enlightened management. London: National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO).

King M, Jones L, McCarthy O, et al. (2008). Development and pilot evaluation of a complex intervention to improve experienced continuity of care in patients with cancer. British Journal of Cancer 100(2): 274-80.

Leydon GM, Boulton M, Moynihan C. (2000). Cancer patients' information needs and information seeking behaviour: in depth interview study. BMJ 320, no. 7239 (2000): 909-13.

Lancet, The. (2011). Specialist nurses and lung cancer. The Lancet 377.9781 (2011): 1892.

Llewellyn C, McGurk J, Weinman M. (2006). How satisfied are head and neck cancer (HNC) patients with the information they receive pre-treatment? Results from the satisfaction with cancer information profile (SCIP). Oral Oncology 42: 726-734.

Lyratzopoulos G, Neal RD, Barbiere JM, et al. (2012). Variation in number of general practitioner consultations before hospital referral for cancer: findings from the 2010 National Cancer Patient Experience Survey in England. Lancet Oncology 13: 353–65.

Macleod U, Mitchell ED, Burgess C, et al. (2009). Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers. British Journal of Cancer 101, no. S2: S92-S101.

Manning D, Dickens C. (2007). Cancer Information and Support Centres: fixing parts cancer drugs cannot reach. European Journal of Cancer Care, 16: 33-38.

Mason J. (2002). Qualitative Researching. SAGE Publications.

McCormick K. (2002). A concept analysis of uncertainty of illness. Journal of Nursing Scholarship, 34(2), 127-131.

McIllmurray M B, Thomas C, Francis B, et al. (2001). The psychosocial needs of cancer patients: findings from an observational study. European Journal of Cancer Care 10(4): 261-69.

Mishel M. (1990). Reconceptualization of the uncertainty in illness theory. Image: The Journal of Nursing Scholarship, 22(4), 256-262.

Munthe C, Sandman L, Cutas D. (2012). Person centred care and shared decision making: implications for ethics, public health and research. Health Care Analysis 20(3): 231-249.

NCIN (National Cancer Intelligence Network)/ Cancer Research UK (2015). Unknown Primary Cancer Stats. http://publications.cancerresearchuk.org/cancerstats/stats_unknown_primary (accessed 15/08/15)

National Institute for Clinical Excellence (2010). NICE clinical guideline 104. Metastatic malignant disease of unknown primary origin. Diagnosis and management of metastatic malignant disease of unknown primary origin. London. NICE.

National Institute for Clinical Excellence (2005). Referral guidelines for suspected cancer (CG27), http://www.nice.org.uk/guidance/cg27

National Institute for Clinical Excellence (2004). Supportive and palliative care: The Manual. London. NICE.

Nazareth I, Jones L, Irving A, et al. (2008). Perceived concepts of continuity of care in people with colorectal and breast cancer – a qualitative case study analysis. European Journal of Cancer Care 17(6): 569-77.

Needleman J, Buerhaus P, Mattke S, et al. (2002) Nurse-staffing levels and the quality of care in hospitals. New England Journal of Medicine 346(22): 1715-22.

NHS Confederation. (2010). Co-ordinated cancer care: better for patients, more efficient. Briefing, Briefing 203.

O'Donnell CA. (2000). Variation in GP referral rates: what can we learn from the literature. Family Practice 17(6): 462-70.

O'Rourke N, Edwards R. (2000). Lung cancer treatment waiting times and tumour growth. Clinical Oncology 2000; 12:141–4.

Pennery E, Mallet J. (2000). A Preliminary study of patients' perceptions of routine follow-up after treatment for breast cancer. European Journal of Oncology Nursing 4(3): 138-45.

Pavlidis N. (2007). Forty years' experience of treating cancer of unknown primary. Acta Oncologia 46: 592–601.

Pollock K, Cox K, Howard P, et al. (2008). Service user experiences of information delivery after a diagnosis of cancer: a qualitative study. Supportive Care in Cancer, 16, 963-973.

Quality Health (2013). Cancer Patient Experience Survey 2012-13: National Report. https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-exerience-survey/2013-national-cancer-patient-experience-survey-reports (Accessed 26/06/2015).

Quill TE, Brody H. (1996). Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. Annals of Internal Medicine 125:763-9.

Rafferty AM, Clarke SP, Coles J, et al. (2007). Outcomes of variation in hospital nurse staffing in English hospitals: cross-sectional analysis of survey data and discharge records. International Journal of Nursing Studies 44(2): 175-82.

Reid, RJ, McKendry R, Haggerty J, et al (2002). Defusing the confusion: concepts and measures of continuity of health care: final report. Canadian Health Services Research Foundation= Fondation canadienne de la recherche sur les Services de santé.

Richardson A, Wagland R, Foster R, et al. (2013). Uncertainty and anxiety in the Cancer of Unknown Primary patient journey: a multi-perspective study. BMJ Supportive and Palliative Care 1–7. doi:10.1136/bmjspcare-2013-000482.

Risberg T, Sorbye SW, Norum J, et al. (1996). Diagnostic delay causes more psychological distress in female than in male cancer patients. Anticancer Research 16(2): 995-1000.

Roberts K, Lepore S, Urken M. (2008). Quality of life after thyroid cancer: an assessment of patient needs and preferences for information and support. Journal of Cancer Education, 23, 186-191.

Rose PW, Rubin G, Perera-Salazar R, et al. (2015). Explaining variation in cancer survival between 11 jurisdictions in the International Cancer Benchmarking Partnership: a primary care vignette survey. BMJ Open 2015;5: e007212. doi:10.1136/bmjopen-2014-007212.

Rutten L, Finney J, Neeraj, K et al. (2005). Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). Patient Education and Counselling 57(3): 250-61.

Ryan RC, Lawlor PG, Walshe JM. (2010). Cancer of unknown primary: addressing the communicative, ethical and medical challenges in clinical practice – a perspective from palliative care and supportive oncology. Progress in Palliative Care 18(5): 291-296.

Sandoval GA, Levinton C, Blackstien-Hirsch P, et al. (2006). Selecting predictors of cancer patients' overall perceptions of the quality of care received. Annals of Oncology 17(1): 151-56.

Shaha M, Cox C, Talman K, et al. (2008) Uncertainty in breast, prostate, and colorectal cancer: implications for supportive care. Journal of Nursing Scholarship, 40(1): 60-67.

Shine, KI. (2002). Health care quality and how to achieve it. Academic Medicine 77(1): 91-99.

Smith SDM, Nicol KM, Devereux J, et al. (1999) Encounters with doctors: quantity and quality**.** *Palliative Medicine.* 13:217-223.

Sullivan CO, Rumana ZO, Ambler G, et al. (2005). Case-mix and variation in specialist referrals in general practice. British Journal of General Practice 55, no. 516 (2005): 529-33.

Sullivan A, Elliott S. (2007). Assessing the value of a cancer clinical nurse specialist. C*ancer Nursing Practice* 6(10): 25-28.

Symons J, James N. (2009). Dilemmas in managing patients with cancer of unknown primary. Cancer Nursing Practice, 8(8), 27-32.

Trevatt P, Leary A. (2010). A census of the advanced and specialist cancer nursing workforce in England, Northern Ireland and Wales. European Journal of Oncology Nursing 14(1): 68-73.

Walsh R, Harrison JD, Young JM, et al. (2010). What are the current barriers to effective cancer care coordination? A qualitative study. BMC Health Services Research 2010, 10:132 http://www.biomedcentral.com/1472-6963/10/132

Appendix 1. Taxonomy of definitions for CUP

Terms used in NICE guideline to define CUP	
Malignancy of undefined primary origin (MUO)	Metastatic malignancy identified on the basis of a limited number of tests, without an obvious primary site, before comprehensive investigation
Provisional carcinoma of unknown primary origin (provisional CUP)	Metastatic epithelial or neuro-endocrine malignancy identified on the basis of the histology or cytology, with no primary site detected despite a selected initial screen of investigations, before specialist review and possible further specialised investigations
Confirmed carcinoma of unknown primary origin (confirmed CUP)	Metastatic epithelial or neuro-endocrine malignancy identified on the basis of final histology, with no primary site detected despite a selected initial screen of investigations, specialist review, and further specialised investigations as appropriate

Source: NICE (2010)

Appendix 2. Department of Health criteria for determining tumour groups from ICD-10 codes.

ICD-10 Four Character Sub-Category Code	Tumour Grouping	ICD-10	Description
C770	Head and Neck	C77	Secondary and unspecified malignant neoplasm: Lymph nodes of head, face and neck
C771	Other	C77	Secondary and unspecified malignant neoplasm: Intrathoracic lymph nodes
C772	Other	C77	Secondary and unspecified malignant neoplasm: Intra-abdominal lymph nodes
C773	Other	C77	Secondary and unspecified malignant neoplasm: Axillary and upper limb lymph nodes
C774	Other	C77	Secondary and unspecified malignant neoplasm: Inguinal and lower limb lymph nodes
C775	Other	C77	Secondary and unspecified malignant neoplasm: Intrapelvic lymph nodes
C778	Other	C77	Secondary and unspecified malignant neoplasm: Lymph nodes of multiple regions
C779	Other	C77	Secondary and unspecified malignant neoplasm: Lymph node, unspecified
C780	Lung	C78	Secondary malignant neoplasm of lung
C781	Lung	C78	Secondary malignant neoplasm of mediastinum
C782	Lung	C78	Secondary malignant neoplasm of pleura
C783	Lung	C78	Secondary malignant neoplasm of other and unspecified respiratory organs
C784	Colorectal / Lower Gastrointestinal	C78	Secondary malignant neoplasm of small intestine
C785	Colorectal / Lower Gastrointestinal	C78	Secondary malignant neoplasm of large intestine and rectum
C786	Other	C78	Secondary malignant neoplasm of retroperitoneum and peritoneum
C787	Upper Gastrointestinal	C78	Secondary malignant neoplasm of liver and intrahepatic bile duct
C788	Colorectal / Lower Gastrointestinal	C78	Secondary malignant neoplasm of other and unspecified digestive organs
C790	Urological	C79	Secondary malignant neoplasm of kidney and renal pelvis

C791	Urological	C79	Secondary malignant neoplasm of bladder and other and unspecified urinary organs
C792	Skin	C79	Secondary malignant neoplasm of skin
C793	Brain/Central Nervous System	C79	Secondary malignant neoplasm of brain and cerebral meninges
C794	Brain/Central Nervous System	C79	Secondary malignant neoplasm of other and unspecified parts of nervous system
C795	Other	C79	Secondary malignant neoplasm of bone and bone marrow
C796	Gynaecological	C79	Secondary malignant neoplasm of ovary
C797	Other	C79	Secondary malignant neoplasm of adrenal gland
C798	Other	C79	Secondary malignant neoplasm of other specified sites
C799	Other	C79	Secondary malignant neoplasm, unspecified site
C800	Other	C80	Malignant neoplasm, primary site unknown, so stated
C809	Other	C80	Malignant neoplasm, unspecified
C80X	Other	C80	Malignant neoplasm, without specification of site

Appendix 3. Search strategies and results for areas of interest in the CUP FT data.

Category	Year	Search results(n)	Coded (n)	% of search results coded	Search results coverage (%)	vs. WCPES coverage (%)	Search terms
Nursing	2010	1098	920	83.7%	36.1%	22.9%	“Nurs*”
	2011-12	804	688	85.5%	25.5%		
	2013	985	805	81.7%	32.2%		
Communication	2010	1247	842	67.5%	41.0%	16.3%	“Communication” OR
	2011-12	1284	856	66.6%	40.7%		
	2013	1121	738	65.8%	36.6%		
Surgery	2010	566	450	79.5%	18.6%	11.6%	“Surg*”
	2011-12	623	510	81.8%	19.7%		
	2013	519	409	78.8%	16.9%		
Consultants	2010	145	111	76.5%	4.8%	10.0%	“Consultant*” OR “specialist*” OR “oncologist” OR “surgeon” OR “radiologist” OR “senior doctor”
	2011-12	253	198	78.2%	8.0%		
	2013	185	143	77.2%	6.1%		
Clinical Nurse Specialists	2010	72	67	93.0%	2.3%	4.5%	“Clinical Nurse Specialist” OR “CNS” OR “specialist nurse”
	2011-12	112	101	90.1%	3.6%		
	2013	106	100	94.3%	3.5%		
GP	2010	397	309	77.8%	10.2%	8.6%	"GP" OR "G.P" OR "general practitioner" OR "family doctor"
	2011-12	439	319	72.7%	10.1%		
	2013	373	300	80.4%	9.8%		
Post-treatment care	2010	123	45	36.6%	1.5%	6.2%	aftercare OR ''after care'' OR monitor* OR follow-up OR ''follow up''
	2011-12	121	43	35.5%	1.4%		
	2013	152	55	36.2%	1.8%		
Emotional, Social & Psychological needs	2010	194	63	32.5%	2.1%	2.8%	emot* OR counsell* OR depress* OR anxi* OR fear* OR cope OR coping OR lonel* OR isolat* OR therap* OR mental
	2011-12	185	46	24.9%	1.5%		
	2013	146	39	26.7%	1.3%		

Palliative Care	2010	51	44	86.3%	1.5%	.	palliative* OR hospice*
	2011-12	66	49	74.2%	1.6%		
	2013	56	41	73.2%	1.3%		
Investigations	2010	269	171	63.6%	5.6%	10.2%	Investiga* OR test* OR diag* OR scan OR MRI OR biopsy OR mammogram OR PSA OR P.S.A OR result*
	2011-12	297	201	67.7%	6.4%		
	2013	301	200	66.4%	6.6%		
Finances	2010	115	67	58.3%	2.2%	0.8%	financ* OR money OR benefit* OR claim* OR expens* OR income OR employ* OR unemploy* park* OR meter
	2011-12	118	61	51.7%	1.9%		
	2013	185	54	29.2%	1.8%		
A&E	2010	204	25	12.3%	0.8%	0.9%	A&E OR "A and E" OR Emergency OR Casualty OR "Accident and Emergency"
	2011-12	218	29	13.3%	0.9%		
	2013	208	28	13.5%	0.9%		
Chemotherapy	2010	494	364	73.7%	12.0%	6.5%	Chemo*
	2011-12	534	375	70.2%	11.9%		
	2013	462	321	69.5%	10.5%		
Radiotherapy	2010	209	82	39.2%	2.7%	5.4%	Radio*
	2011-12	218	123	56.4%	3.9%		
	2013	193	88	45.6%	2.9%		

Appendix 4. Respondent demographics

The demographic characteristics for patients with CUP who responded to CPES include data on their age, gender, other reported long-standing health conditions, employment status (for 2013 only) and sexual orientation. Data for ethnicity was incomplete.

3.1 Age groups

The majority of CUP free-text respondents fell into the 51-65 & 66-75 years age groups. The distribution of percentages of participants across the age groups was also stable broadly across the periods of observation, with all differences between observation periods <10% and most <5% (see figure 1 and tables 1-3). The percentages of respondents were also broadly comparable between the CUP FT and total CPES respondent groups for all three periods of observation, with all under >10% and most <5%.

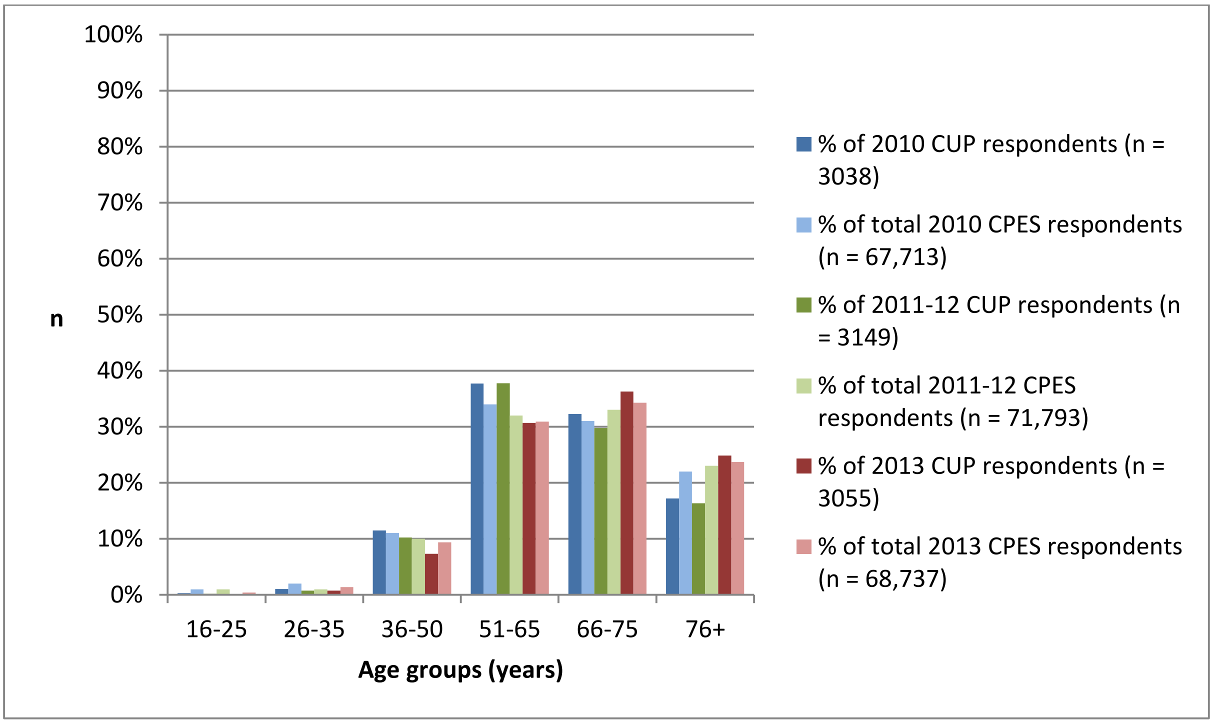

Figure 1 - Percentages of CUP free-text & total CPES respondents by age group.

Age groups	Number of CUP free-text respondents	% of 2010 CUP free text respondents (n = 3038)	% of total 2010 CPES respondents (n = 67,713)[3]
16-25	8	>1%	1%
26-35	32	1%	2%
36-50	349	11%	11%
51-65	1145	38%	34%
66-75	981	32%	31%
76+	523	17%	22%

Table 1 - Numbers and percentages of 2010 CUP free-text and total CPES respondents by age group.

Age groups	Number of CUP free-text respondents	% of 2011-12 CUP free-text respondents (n = 3149)	% of total 2011-12 CPES respondents (n = 65,745)
16-25	6	0%	1%
26-35	24	1%	1%
36-50	322	10%	10%
51-65	1189	38%	32%
66-75	938	30%	33%
76+	514	16%	23%
Data unavailable[4]	156	5.0%	

Table 2 - Numbers and percentages of 2011-12 CUP free-text and total CPES respondents by age group.

Age groups	Number of CUP free-text respondentss	% of 2013 CUP free-text respondents (n = 3055)	% of total 2013 CPES respondents (n = 68,737)[5]
16-25	4	0.1%	0.4%
26-35	22	0.7%	1.4%
36-50	224	7.3%	9.4%
51-65	938	30.7%	30.9%
66-75	1108	36.3%	34.3%
76+	759	24.8%	23.7%

Table 3 - Numbers and percentages of 2013 CUP free-text and total CPES respondents by age group.

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[3] Percentages for age groups in the main CPES are those reported by Quality Health in their 2010 National CPES report. =<1% values have been reported as 1% in these data for 2010 & 2011-12.

[4] For 2010 and 2013, sample data were used for year of birth, and thus data were available for 100% of cases; for 2011-12, only those years of birth provided by respondents were used, hence the 'data missing' values.

[5] Percentages for this year are given to 1dp, as this standard was adopted in the 2013 Quality Health National CPES Report.

3.2 Gender

The distribution of CUP patients who provided comments across the three periods of observation was broadly comparable for both men and women, with all differences between the periods <5% for both sex groups. Figure 2 below compares the proportion of male and female respondents with CUP for each year of observation with the total proportion of CPES respondents for that year. Figures indicate that for each year consistently lower percentages of men with CUP provided comments to the CPES than male respondents in general, while consistently more women with CUP provided comments than the overall percentage for female CPES respondents.

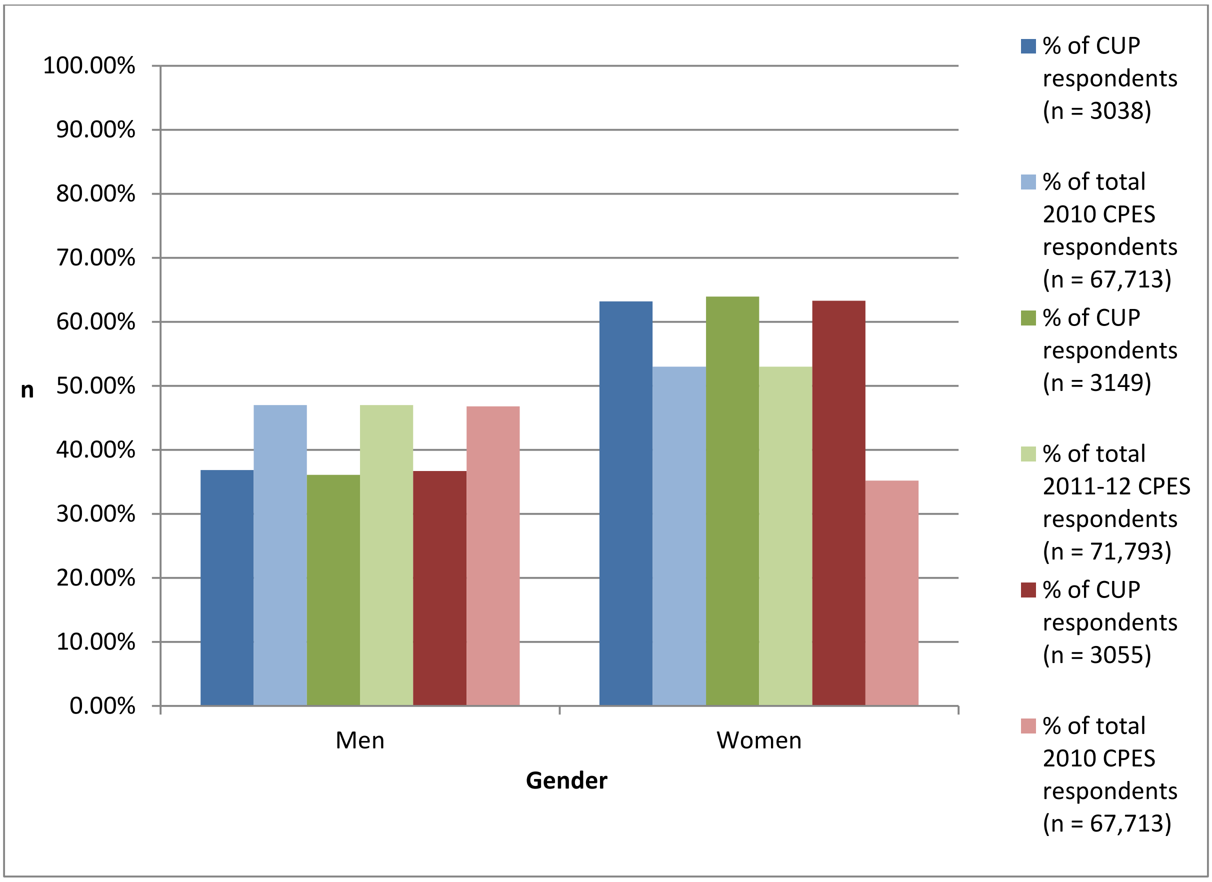

Figure 2 - Percentages of CUP free-text and total CPES respondents by sex.

Sex	n=	% of CUP free-text respondents (n = 3038)	% of total 2010 CPES respondents (n = 67,713)
Men	1119	36.8%	47%
Women	1919	63.2%	53%

Table 4 - Numbers and percentages of 2010 CUP free-text and total CPES respondents by sex.

Sex	n=	% of CUP free-text respondents (n = 3149)	% of total 2011-12 CPES respondents (n = 71,793)
Men	1136	36.0%	47%
Women	2013	63.9%	53%

Table 5 - Numbers and percentages of 2011-12 CUP free-text and total CPES respondents by sex.

Sex	n=	% of CUP FT respondents (n = 3055)	% of total 2013 CPES respondents (n = 68,737)
Men	1121	36.7%	46.8%
Women	1934	63.3%	35.2%

Table 6 - Numbers and percentages of 2013 CUP FT and total CPES respondents by sex.

3.3 Longstanding conditions

The majority of participants did not declare a long-term condition in addition to their cancer (this was the case for all three periods of observation, as well as the CUP free-text and total CPES respondent groups). For those who did declare a long-standing condition, percentages within the different condition groups were similar across the three periods of observation (i.e. differences <5%), as well as between the CUP free-text & total CPES groups (i.e. differences <5%).

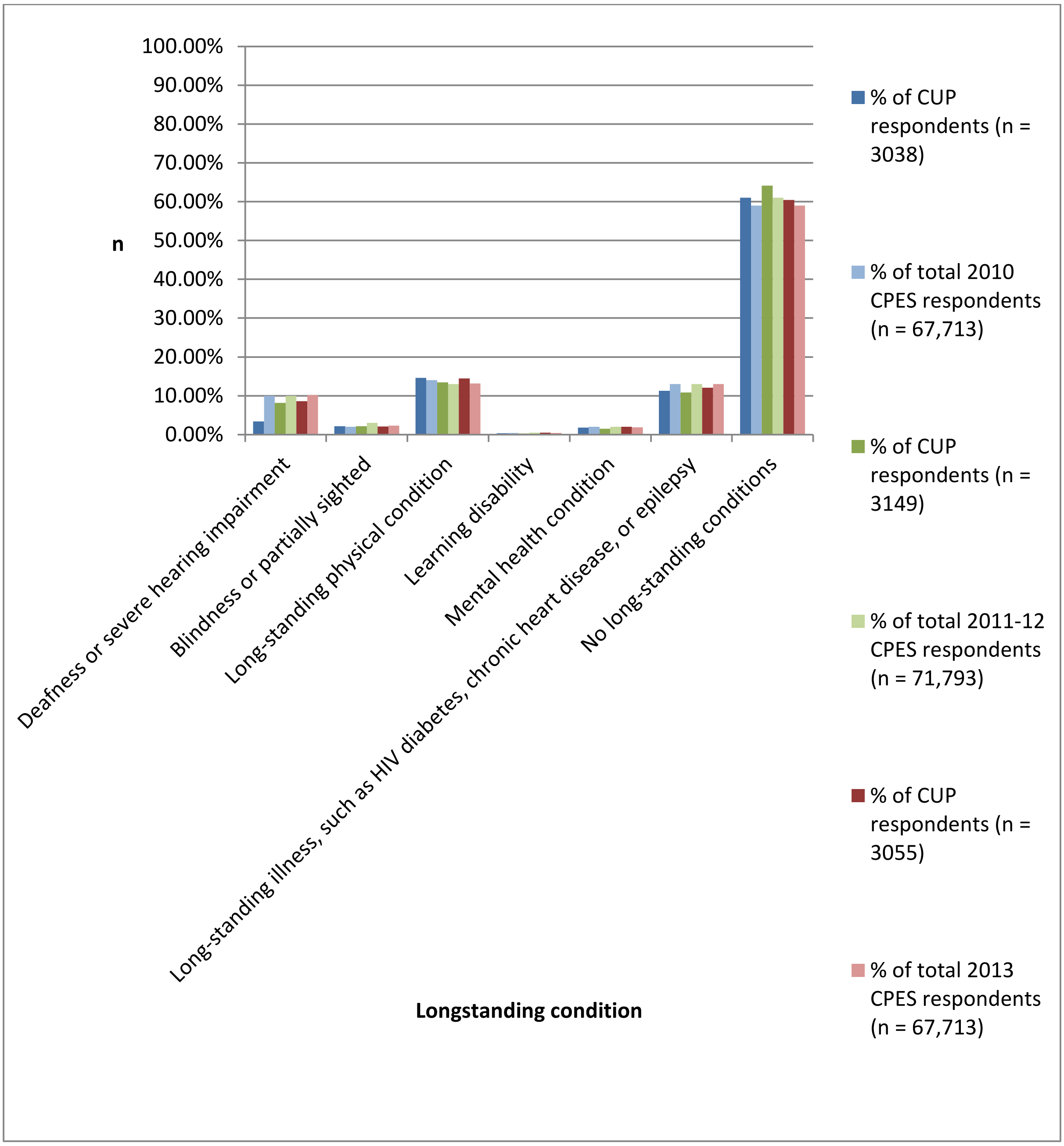

Figure 3- Percentages of CUP free-text and total CPES respondents in relation to long-standing conditions.

Condition	n=	% of 2010 CUP free-text respondents (n = 3038)	% of total 2010 CPES respondents (n = 67,713)
Deafness or severe hearing impairment	104	3.4%	10%
Blindness or partially sighted	66	2.2%	2%
Long-standing physical condition	444	14.6%	14%
Learning disability	10	0.3%	0.40%
Mental health condition	54	1.8%	2%
Long-standing illness, such as HIV diabetes, chronic heart disease, or epilepsy	343	11.3%	13%
No long-standing conditions	1854	61.0%	59%

Table 7 - Numbers and percentages of 2010 CUP free-text and total CPES respondents in relation to long-standing conditions.

Condition	n=	% of 2011-12 CUP free-text respondents (n = 3149)	% of total 2011-12 CPES respondents (n = 71,793)
Deafness or severe hearing impairment	258	8.2%	10%
Blindness or partially sighted	69	2.2%	3%
Long-standing physical condition	424	13.5%	13%
Learning disability	9	0.3%	0.5%
Mental health condition	48	1.5%	2%
Long-standing illness, such as HIV diabetes, chronic heart disease, or epilepsy	341	10.8%	13%
No long-standing conditions	2019	64.1%	61%

Table 8 - Numbers and percentages of 2011-12 CUP free-text and total CPES respondents in relation to long-standing conditions.

Condition	n=	% of 2013 CUP free-text respondents (n = 3055)	% of total 2013 CPES respondents (n = 68,737)
Deafness or severe hearing impairment	262	8.6%	10.2%
Blindness or partially sighted	63	2.1%	2.3%
Long-standing physical condition	443	14.5%	13.2%
Learning disability	14	0.5%	0.4%
Mental health condition	62	2.0%	1.9%
Long-standing illness, such as HIV diabetes, chronic heart disease, or epilepsy	368	12.1%	13.0%
No long-standing conditions	1847	60.5%	59.0%

Table 9 - Numbers and percentages of 2013 CUP free-text and total CPES respondents in relation to long-standing conditions.

3.4 Employment status

We are only able to report employment status for 2013 participants, as collection of these data did not begin until the 2013 CPES. The majority of patients with CUP who provided comments were retired, with the second largest group being those in full time employment (table 10). All percentages were comparable with the proportions relating to total CPES respondents (i.e. <5%).

Status	n=	% of CUP free-text respondents (n = 3055)	% of total 2013 CPES respondents (n = 68,737)[6]
Full time employment	372	12.2%	16.5%
Part time employment	226	7.4%	8.9%
Homemaker	101	3.3%	2.7%
Student (in education)	0	0.0%	0.3%
Retired	1914	62.7%	62.9%
Unemployed - and seeking work	14	0.5%	0.7%
Unemployed - unable to find work for health reasons	222	7.3%	5.7%
Other	62	2.0%	2.2%
Data unavailable	144	4.7%	
Total	3055	100.0%	

Table 10 - numbers and percentages of 2013 CUP FT and total CPES respondents by employment status.

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[6] The data provided by Quality Health for 2013 CUP free text respondents contain missing variables for 144 cases. However, figures provided in the Quality Health do not account for missing cases. In the 2013 National CPES report the total number of respondents (n = 68,737) does not equal the number of cases reported across the categories of employment reported (n = 65,694). This leaves 3043 cases unaccounted.

3.5 Sexual orientation

The vast majority of patients with CUP who provided comments and total CPES respondents identified as being heterosexual. In both sets of data, the values for all other individual sexual orientations was <1%.

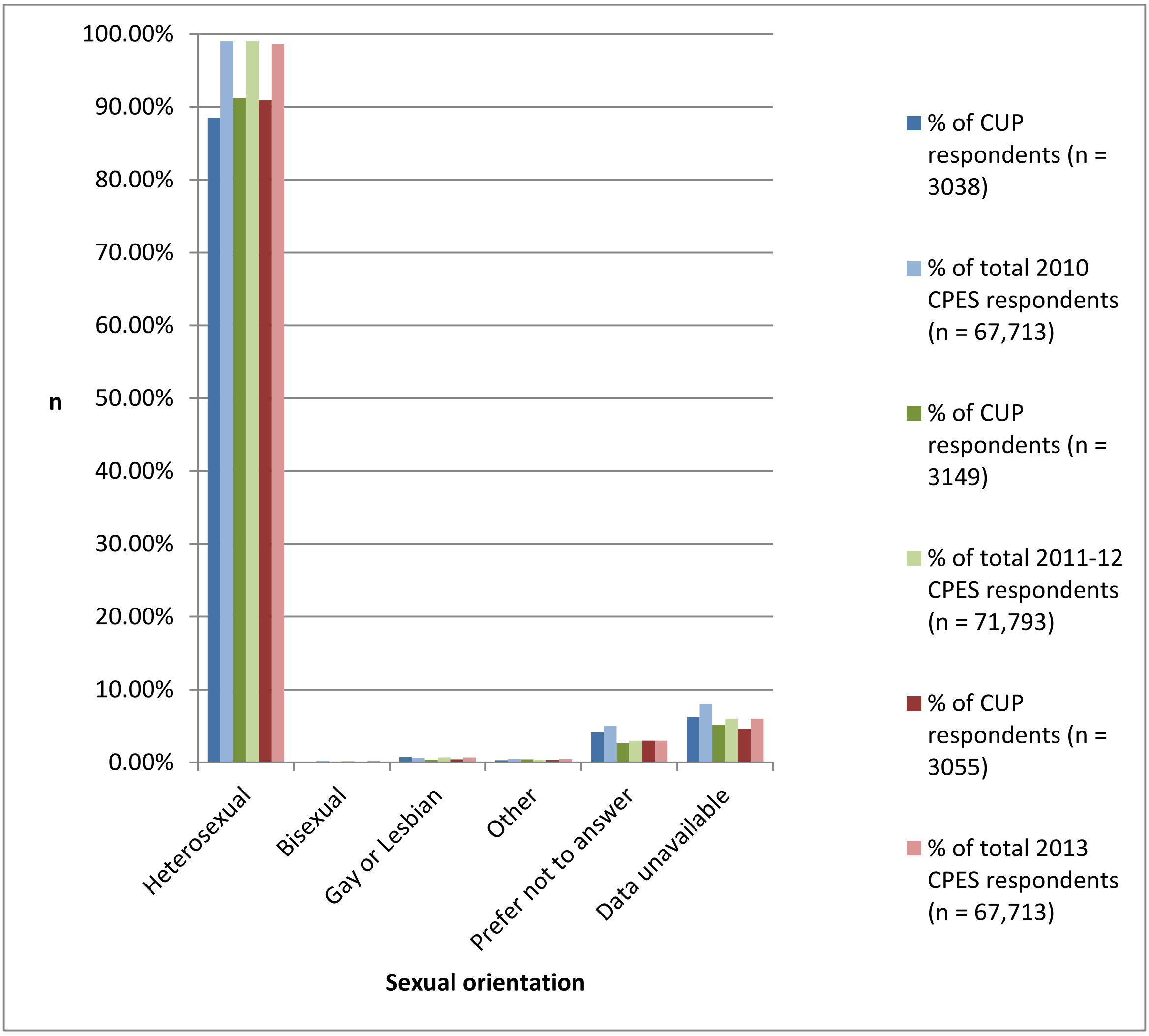

Figure 4 - percentages of CUP free-text and total CPES respondents by sexual orientation.

Sexual orientation	n=	% of CUP free-text respondents (n = 3038)	% of total 2010 CPES respondents (n = 67,713)[7]
Heterosexual	2688	88.5%	99%
Bisexual	3	0.1%	0.2%
Gay or Lesbian	22	0.7%	0.6%
Other	10	0.3%	0.5%
Prefer not to answer	125	4.1%	5%
Data unavailable	190	6.3%	8%

Table 11 - Numbers and percentages of 2010 CUP FT and total CPES respondents by sexual orientation.

Sexual orientation	n=	% of CUP free-text respondents (n = 3149)	% of total 2011-12 CPES respondents (n = 71,793)
Heterosexual	2872	91.2%	99%
Bisexual	4	0.1%	0.2%
Gay or Lesbian	13	0.4%	0.7%
Other	14	0.4%	0.4%
Prefer not to answer	83	2.6%	3%
Data unavailable	163	5.2%	6%

Table 12 - Numbers and percentages of 2011-12 CUP free-text and total CPES respondents by sexual orientation.

Sexual orientation	n=	% of CUP free-text respondents (n = 3055)	% of total 2013 CPES respondents (n = 68,737)
Heterosexual	2778	90.9%	98.6%
Bisexual	3	0.1%	0.2%
Gay or Lesbian	13	0.4%	0.7%
Other	11	0.4%	0.5%
Prefer not to answer	91	3.0%	3%
Data unavailable	142	4.7%	6%

Table 13 - Numbers and percentages of 2013 CUP free-text and total CPES respondents by sexual orientation.

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[7] Percentages of total CUP respondents relating to sexual orientation do not equal 100% in this distribution. This is because of the reporting standard used by Quality Health, where only those who had identified with a group were included. The remaining respondents identified with the 'Prefer not to answer' group, or for whom data were missing, appear to have been calculated against the total number of respondents for the respective years.

3.6 ICD-10 codes.

Patents with CUP were identified using the tenth revision of the ICD codes C77, C78, C79 and C80. The table below indicates the numbers and percentages of CUP free-text respondents assigned to each of the four ICD-10 codes over the three periods of observation. The largest group of respondents was coded under C79 (n=3676, 40%), compared with the smallest group coded under c80 (n=553, 6%). The proportions of respondents from within each ICD code remained relatively stable over the three observation points.

ICD code	2010 (n)	2010 (%)	2011-12 (n)	2011-12 (%)	2013 (n)	2013 (%)	Code total (n)	Code total (%)
c77	484	15.9%	526	16.7%	514	16.8%	1524	16.5%
c78	1116	36.7%	1201	38.1%	1172	38.4%	3489	37.8%
c79	1225	40.3%	1242	39.4%	1209	39.6%	3676	39.8%
c80	213	7.0%	180	5.7%	160	5.2%	553	6.0%
Column total	3038	100.0%	3149	100.0%	3055	100.0%	9242	100.0%

Table 7 - numbers and percentages of CUP FT respondents by ICD-10 code.

Identification of CUP patients is recognised as an ongoing issue in research and monitoring. While a widely used conceptual definition of CUP exists (i.e. 'histologically confirmed metastatic cancer for which clinicians are unable to identify a primary tumour after a standard diagnostic approach'), there are concerns that this may exclude, for example, cancers that are not microscopically verified (and therefore under-estimate the population burden of disease) (Brewster et al. 2014). There also exist no internationally agreed diagnostic codes for CUP and recent studies such as that conducted by Brewster et al. (2014) have, for example, augmented the standards used by DH (i.e. C77-C80) by using additional codes used by the International Agency for Research on Cancer (IARC – i.e. C26, 39, 48 & 76). These are live issues for the study of CUP more generally in terms of how the population is defined and identified. If the ICD codes used to define CUP were expanded there would consequently be more comments for analysis.