

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

**Executive Summary 10<sup>th</sup> September 2015**

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*Commissioned and funded by The CUP Foundation  
with additional funding from the University of  
Southampton's 'Adventures in Research' funding*

cancer of  
unknown  
primary  
foundation

The logo for Jo's Friends, featuring a stylized blue infinity symbol with the text "Jo's friends" inside it.

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This report should be referenced as: Wagland R, Bracher M, Esqueda AI, Schofield P, Richardson A. (2015) Experiences of Care of Patients with Cancer of Unknown Primary (CUP): Analysis of the 2010, 2011-12 & 2013 Cancer Patient Experience Survey (CPES) England. Southampton: University of Southampton.

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## **Acknowledgements**

This study was commissioned and funded by the Cancer of Unknown Primary (CUP) Foundation. Additional funding was provided by the 'Adventures in Research' funding stream at the University of Southampton. We would like to thank Quality Health, who were commissioned by NHS England to administer the Cancer Patient Experience Survey (CPES), for providing the de-identified free-text data.

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

## Introduction

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, and statistics indicate a 20% one year survival. The National Institute of Clinical Excellence (NICE) published guidelines for the management of CUP patients in 2010. However, there is little published research on quality of life (QoL), psychosocial aspects of CUP and experiences of treatment and care.

The national Cancer Patient Experience Survey (CPES) is an extensive, England-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), and invites participation from all patients with a cancer diagnosis in receipt of inpatient or day care.

This executive summary provides a summary of the findings. More detail regarding methodology and results of this work can be found in the full Final Report, which includes anonymised patient comments as exemplars of themes that emerged from the data.

## Aims and objectives

The aim of this study was to analyse the reported experiences of CUP patients within the free-text questions of successive CPES surveys. Data were available for three observation points (2010; 2011-12; 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;
- Describe aspects of care patients with CUP would like to see improved

## Methodology

Quality Health administered a population-based postal survey at three points of observation: 2010, 2011-12 and 2013. Each 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.<sup>1</sup> The research team conducted a secondary analysis of data collected during these surveys.

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

## Cohort identification

All NHS health trusts treating adult patients with cancer in England were included.<sup>2</sup> 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).

## Questionnaire and design content

Questionnaires included questions on socio-demographics, quality of treatment and care, disease status and long term conditions (LTCs). 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?

## Survey process

The survey was distributed by post, with two reminders sent out to non-responders only. Covering letters were sent out on hospital trust headed paper and signed by a member of the trust's staff, usually the chief executive. 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.

## Data analysis

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

- **Stage 1: Data sorting into comment categories:** Data were sorted according to the thematic taxonomy developed from a previous study of CPES free-text data: the national CPES in Wales (2013). Search criteria were developed for each category to identify relevant comments.
- **Stage 2: Detailed coding of comment categories:** Once all comments were coded to stage one level, individual categories were subjected to a second stage of more detailed sorting to explore content within different areas of cancer care.
- **Stage 3: Identification of overarching themes across comment categories:** Overarching themes emerged from the data that referred to aspects of cancer care that cut across different comment categories and phases of the cancer journey.

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<sup>2</sup> In 2013 this was 155 NHS Trusts, down from 160 in 2011-12 and 158 in 2010.

## Findings

In total, the CUP CPES data received from Quality Health contained 9242 free text comments across the three periods of observation (2010: 3038 comments; 2011-12: 3149 comments; 2013: 3055 comments). Table 1 shows the demographic characteristics of the patients with CUP who provided these comments, which remained relatively constant across the three surveys. Men consistently comprised just over a third of those who responded with comments, with the majority of patients being within the 51-65 and 66-75 year age groups.

**Table 1: Demographic background for CPES respondents with CUP**

Characteristic	2010 (n=3038)		2011-12 (n=3149)		2013 (n=3055)	
	n=	%	n=	%	n=	%
<b>Gender</b>						
Men	1119	36.8	1136	36.1	1121	36.7
Women	1919	63.2	2013	63.9	1934	63.3
<b>Age groups</b>						
16 – 25 years	8	>1	6	0	4	0.1
26 – 35 years	32	1	24	1	22	0.7
36 – 50 years	349	11	322	10	224	7.3
51 – 65 years	1145	38	1189	38	938	30.7
66 – 75 years	981	32	938	30	1108	36.3
76+ years	523	17	514	16	759	24.8

The findings of this report present a range of experiences from patients in England with a CUP diagnosis, providing many examples of positive care but also areas for concern. Comments were retrieved from the dataset in seventeen categories, which were organised into four groups: cross cutting issues; health care professionals; treatment specialisms; and other quality of life concerns (Table 2). For each of the comment categories, Table 2 shows the following: the number of patients who provided such 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 by CUP patients coded within them.

Overall, the proportion of patients who provided comments on each of the themes remained relatively consistent over the three CPES observation periods. Ratios of negative to positive comments were similarly consistent, though with slight variations for some themes. For example, there was a small increase in the proportion of negative to positive comments amongst patients describing experiences with their GP in 2013 over the previous two time-points. This suggests that patients' experiences with GPs did not improve over the three CPES observation points.

Of the seventeen categories, comments were in varying degrees predominantly negative for nine and were predominantly positive for eight. The category with the highest 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 predominantly positive experiences for most treatment categories (e.g. surgery, chemotherapy, radiotherapy and palliative care), and reported

**Table 2: Framework of comment categories with counts and ratios of positive and 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 (%)
<b>1. Cross cutting issues</b>						
<b>Inter-agency Communication</b>	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
<b>Staff communication with patients</b>	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
<b>Waiting for appts/ investigations to be arranged</b>	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
<b>Waiting time on the day</b>	2010	372	10	37.2	- ve	12.6
	2011-12	352	10	35.2	- ve	11.5
	2013	299	12	24.9	- ve	10.2
<b>Investigations – receiving results</b>	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
<b>2. Health care professions</b>						
<b>GPs</b>	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
<b>Consultants</b>	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
<b>Nursing</b>	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
<b>Clinical Nurse Specialists (CNS)</b>	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
<b>3. Treatment specialisms</b>						
<b>Accident &amp; Emergency</b>	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
<b>Chemotherapy</b>	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
<b>Radiotherapy</b>	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
<b>Surgery</b>	2010	175	380	0.46	+ ve	18.2
	2011-12	195	430	0.45	+ ve	19.0
	2013	170	350	0.49	+ ve	17.0
<b>Palliative care</b>	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
<b>Post-treatment care</b>	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
<b>4. Other quality of life concerns</b>						
<b>Emotional, social and psychological needs</b>	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
<b>Financial concerns</b>	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

mostly negative comments only for 'Accident & Emergency' and for 'Post-treatment care'.

The category under which comments were overwhelmingly negative was 'Waiting on the day for appointments', with a mean 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 is an overwhelmingly negative experience for patients with CUP. '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 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.

## Overarching themes

Stage three analysis of the coded categories of comments identified the following overarching themes that cut across the categories of coded data. These themes have been organised under two sub-headings: coordination of care; and person-centred care.

### 1. Coordination of care.

**Specialist referral and diagnosis.** Unless admitted as an emergency, cancer care does not normally commence for a patient until they have been referred for a specialist consultation by their GP. Comments often indicated patients had presented with symptoms to GPs for months, and sometimes years before diagnosis and/or referral. Delays for investigations, secondary referral and treatment were often reportedly caused through 'misdiagnosis', with GPs either treating patients symptomatically or relating symptoms to a health problem other than cancer. Comments suggested that many instances of delayed diagnosis could have been prevented had GPs more often taken the concerns of their patients seriously.

**Communication between health agencies.** Comments portrayed a high level of poor experiences of communication between different health sectors (e.g. primary and secondary), different providers (e.g. trusts), and between different hospital departments and health professionals within the same trust. Clinical teams were sometimes perceived to be working in 'silos', with each team concerned with treating '*only a part of their bodies*' and not '*the whole person*'. Patients with advanced cancer and cancer of unknown primary will often have treatment across a number of clinical teams and multi-disciplinary teams (MDTs), and if they do not communicate well with one another patients will experience care that is dis-jointed. Communication could be particularly poor between secondary and primary care, with frequent reports by patients that their GPs were unaware of their cancer treatment.

**Investigations and treatment.** Many patients with CUP described delays occurring when their care was referred to other clinical teams and investigation reports were often misfiled, lost, or were not



available at outpatient clinic appointments. Such lack of coordination could lead to delays to treatment and created greater anxiety for patients.

**Continuity of care.** Continuity of care involves management and relational continuity. However, in addition to clinical teams reportedly working in silos and information not being passed between clinical teams, CUP patients often also reflected on the large number of health professionals they came into contact with and the concern that no-one appeared to have overall responsibility for their care. A potential cause of stress and anxiety for patients.

**Post-treatment care:** Comments often did not describe specific issues related to post-treatment care, other than its lack. Patients conveyed a sense of anxiety and uncertainty concerning possible recurrence (if they believed they were in remission) and the effectiveness of services to monitor this. They were also concerned about receiving insufficient information and support from health professionals to help them deal with the effects of cancer and its treatment.

**Coordination role of CNSs.** Many patients described their experiences with CNSs, and these comments were overwhelmingly positive. CNSs were viewed as vitally important by patients in the coordination and explanation of their care. Almost all negative comments concerning CNSs related to patients reporting a lack of access to one, often blamed upon economic constraints and cost cuts.

## 2. Person-centred care

**Courteous and respectful treatment.** Patients 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. Many patients reported positive experiences where they were treated as '*a person*' or '*a human being*' rather than '*a set of symptoms*'. Sometimes concerns about not being treated respectfully related to low staffing levels.

**Appointment waiting times.** Patients very often reported long delays for clinic appointments. These delays could cause much stress when waiting for investigation results, and delays could also impact upon work and family commitments. Patients were sometimes concerned about overrunning car park charges. While recognising delays might be unavoidable, patients suggested that courteously informing them of the length of delays may alleviate some stress.

**Informing patients of diagnosis.** The manner in which patients were informed of their diagnosis by health professionals (e.g. GPs or hospital doctors) could have significant impact upon their emotional and psychological wellbeing. Patients who provided positive comments describing the way they were informed involved being treated respectfully and courteously, with some form of hope being conveyed by health professionals. Poor experiences of being informed of their diagnosis included being emotionally unprepared, being told too abruptly and brusquely, often in a busy environment with little privacy.

**Patient information.** Some patients received apparently conflicting explanations from health professionals concerning investigations and treatment options, which undermined their confidence

in the care they were receiving. Patients often felt they needed to be assertive with health professionals to ensure they received all the information they needed about their condition and treatment. There were many who felt doctors and nurses would sometimes exercise '*a professional vagueness*' and not fully answer their questions.

**Patient preparation.** The need to be prepared for the effects of cancer and its treatment was a theme that ran through many of the responses. Preparation primarily meant being provided with information concerning the possible treatment side effects and advice about self-management strategies that would address those problems. Some patients had also wanted more information on possible treatment options and for more opportunity to participate in informed decision-making about their treatment.

**Emotional support.** Outstanding psychological needs primarily concerned fears around diagnosis, treatment options and side effects, prognosis and uncertainty about the future. Some patients gave positive comments relating to support services or reflected a desire for more information on support services. However, the majority of comments indicated that staff could most effectively meet patients' emotional needs in the main phases of the cancer journey with improved communication skills and greater sensitivity. In many cases emotional needs were related to the importance of staff conveying a sense of hope, however limited a patient's life expectancy. While emotional problems were described throughout the patient journey, problems were most frequently reported to be acute once active treatment had been completed.

**Financial concerns.** Some patients reflected they would have welcomed advice on claiming benefits for which they were eligible. These were often related to other concerns, such as caring responsibilities for children or older relatives and about loss of earnings during treatment, especially if patients were self-employed. Another issue of concern and irritation was the cost of car parking at hospitals, and some reported the added expense caused by long waiting times on the day for outpatient appointments.

**Person-centred care from CNSs.** As with their role in coordination, the role of the CNS in ensuring person-centred care was considered vital. Many patients described the importance of a CNS as a point of contact who provided information and explanations in terms they could understand, and who were very important in helping patients maintain trust in their care.

## Key messages

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:

- Their concerns about 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;

- 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;
- To be kept informed of the reasons for and lengths of delays in referrals for investigations and for appointments 'on the day';
- 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;
- 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.

## **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.