

# **An audit of acute oncology services: Patient experiences of admission procedures and staff utilisation of a new telephone triage system**

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## **ABSTRACT**

### **Objectives**

In 2010, St James's Institute of Oncology (Leeds, UK) created a new acute oncology service (AOS) consisting of a new admissions unit with a nurse-led telephone triage (TT) system.

This audit cycle (March 2011 and June 2013) evaluated patient experiences of the reconfigured AOS and staff use of the TT system.

### **Methods**

Patient views were elicited via a questionnaire and semi-structured interviews. The TT forms were analysed descriptively evaluating completion and data quality, reported symptoms and their severity; and advice given (including admission rates).

### **Results**

Patients (n=40) reported high satisfaction with the new AOS. However, 56% of patients delayed 2 days or more before contacting the unit.

In 2011, 26% of all admitted patients were triaged via the TT system; 133 TT forms were completed. In June 2013, 49% of admitted patients were triaged; 264 forms were completed.

The most commonly-reported symptoms on the TT forms were pain, pyrexia/rigors/infection, diarrhoea, vomiting and dyspnoea. Half of patients using the TT system were admitted (52% in 2011, 49% in 2013)

### **Conclusions**

Our audit provided evidence of successful implementation of the TT system with the number TT forms doubling from 2011 to 2013. The new AOS was endorsed by patients, with the majority satisfied with the care they received.

## **BACKGROUND**

Over 250,000 patients in the UK are diagnosed with cancer each year.[5] Increasing numbers receive treatments with significant side-effects, some of which, without appropriate action, may become life-threatening.[10] About 18% of cancer patients present to emergency services whilst on treatment,[9, 10] over half of whom are subsequently admitted.[7]

In England, the total number of inpatient bed-days for cancer patients has fallen, but cancer-related emergency admissions doubled from 2000–1 to 2008–9.[8] There are 300,000 unplanned admissions each year; 140,000 following from presentation to emergency departments, with an average stay of 9.6 days.[3]

Three independent national reviews of cancer services recommended improvements in acute oncology services (AOS) and management of treatment-related adverse events (AEs). The 2008 National Confidential Enquiry Report into Patient Outcome and Death (NCEPOD) established that of patients who died within 30 days of their chemotherapy, 43% had severe AEs. However, in 35% of cases, no AEs were recorded. The report called for changes in hospital services to allow safer administration of treatment, better patient information about AEs, better documentation of AEs and streamlining of acute admissions. The National Chemotherapy Advisory Group (NCAG) endorsed these proposals, recommending expert assessment for patients who develop significant complications during chemotherapy.[5] The National Cancer Peer Review Programme's (NCPRP) manual for cancer services published in 2011[4] advised that AOS should aim to provide 24/7 telephone advice to patients and carers before, during and after treatment.

In 2010 the Royal College of Physicians (RCP) conducted a survey to explore the experiences of cancer patients who had an urgent admission to hospital; involving 262 patients from 16 hospitals and 2 cancer centres. 90% of patients surveyed knew what to do should problems develop, but a significant number felt unwell for 2 or more days before seeking help. Patients observed poor communication and handover between teams. Some reported they would like to see a specialist triage system that might avoid attendance and

waiting in emergency departments. The subsequent RCP working party report defined standards for good practice endorsed by patients and contributed to developing the models for AOS.[8]

### **Clinical setting**

In June 2010, St James's Institute for Oncology (a regional cancer centre based in Leeds, UK, providing comprehensive cancer services to 1,500 patients per day) responded to national guidance[6] by re-organising its AOS.[2] A new unit was created, consisting of a 22-bed acute admission ward (open 24/7), and a 4-bed assessment unit (open 8am to 8pm Mon-Fri) with a dedicated admissions coordinator and 2 nurse practitioner posts.

All patients starting anti-cancer treatment were given an emergency telephone contact and provided with detailed treatment-specific side-effects information.

In order to streamline the admissions, a standardised adverse event (AE) telephone triage (TT) system was implemented based on the United Kingdom Oncology Nursing Society (UKONS) guidelines, which recommended all acute contacts from patients and clinical actions taken to be documented on a standardised pro-forma (**Online Appendix 1**). The form is completed on pen and paper and subsequently scanned in the electronic patient record (EPR). [11] Local clinical educators provided consistent training for staff in use of the form to maintain a standardised approach.

The objectives of the new TT system were: 1) to support nurse decision-making and streamline the procedures for acute admissions; and 2) to standardise the documentation of patients symptoms and AEs which have led to hospital contacts and admissions.

### **AIMS**

The overall aim of this clinical audit was to evaluate the reconfigured AOS in terms of patient experiences during the admission process and staff utilisation of the TT system.

Specific objectives were:

- 1) to explore patient experiences of admission to the AOS, using the RCP audit questionnaire supplemented by semi-structured interviews of admitted patients.
- 2) to analyse the use of the TT system for AE-related phone calls and describe:
  - overall completion and data quality
  - reported symptoms and their severity
  - what advice was given (admission, direction to other services, self-management) and the relation between the advice and symptom severity

The TT system was audited twice, initially in March 2011 within the first year of its introduction, and in June 2013, to examine established use. Patient interviews were conducted in 2011 but a lack of resources prevented this in 2013.

## **MATERIALS AND METHODS**

### **RCP audit and interviews**

#### *Patient sample and recruitment*

The Trust Research and Development department approved the audit as service evaluation and approval from the local research ethics committee was not required.

Eligible patients were those admitted to the acute admissions ward, 18 years or over with a diagnosis of solid tumour or haematological cancer with sufficient English to complete the questionnaire and interview.

During March 2011, we aimed to survey and interview consecutively admitted patients on the AOS. However, as the majority of admitted patients were acutely unwell and many were undergoing medical procedures, it was necessary for the researcher to liaise daily with clinical staff to identify suitable patients.

Clinical staff approached patients and introduced them to the researcher. Patients were asked to complete the questionnaire and following this, those who were well enough and

willing were asked to take part in the semi-structured interview to explore their experiences further.

#### *The RCP acute oncology audit questionnaire.*

The questionnaire was developed by the RCP along with local and national cancer research network patient representatives, for the purpose of conducting a national AOS audit. The 29-item questionnaire asked about diagnosis, treatment regime, symptoms, experience of and satisfaction with the admission process and care within the AOS. It comprised of 27 closed questions with categorical responses, plus two open-ended questions, and took approximately 15 minutes to complete. We substituted 'Macmillan Nurse' with 'Cancer Nurse Specialist', and 'ward 95 or 96' for 'Medical Assessment Unit' to ensure relevance to the local AOS. The full questionnaire is available online in the RCP working party report [8].

#### *Semi-structured interviews.*

Patients who completed the questionnaire were also invited to take part in a semi-structured interview (**Online Appendix 2**) about their experiences of admission. Interviews were conducted on the admissions unit (either at the patients bedside or in a separate room), by a researcher not involved in the patient's clinical care. Although we initially planned to audio-record interviews, this proved impractical with patients receiving acute care. Therefore we took detailed notes which gave us the flexibility to sometimes suspend interviews until a more convenient time, ensuring medical procedures and tests were prioritised.

#### **TT system**

The TT system was implemented to standardise and document patient symptom assessment for every call to the AOAU ward. The system is based on national UKONS [11] guidelines and nurses are asked to complete a form for every call to the ward taken from a

patient or carer, and to use the traffic light system to guide the advice patients are given  
**(Online Appendix 1).**

The form lists pyrexia, rigors, signs of infection, problems with Hickman/PICC lines, bleeding, nausea, vomiting, diarrhoea, sore mouth, constipation, breathlessness, spinal pain, pain and sore hands and feet. The form also allows space for free text to record additional information.

Each listed symptom had a tick box (Yes/No), and then traffic light grading assessment to record the severity of the symptom and determine the appropriate action:

- Green - advice over telephone, ask patient to phone back if still worried;
- Amber - to consider if face to face assessment on the ward is needed; and
- Red - requiring urgent assessment on the ward.

Pain severity was documented differently, on a scale 0-10 in addition to site of pain and current analgesia. A separate pain flowchart was referred to in order to determine appropriate action. For analysis purpose, the pain severity was re-coded into Green (scores 1 - 3), Amber (4 - 6) and Red (7 - 10).

Data was collected from completed TT forms daily when they were awaiting input by the ward clerk to the electronic patient record (EPR) system. Information was extracted on diagnosis, treatment, patient demographics, symptom details and clinical actions.

## **ANALYSIS**

The overall aim of this clinical audit was to evaluate the reconfigured AOS in terms of patient experiences during the admission process and staff utilisation of the TT system.

### **Patient experiences during the admission process**

Questionnaire responses were analysed using crosstabular descriptive statistics (IBM SPSS version 19). As the purpose of collecting the qualitative data was to provide more indepth insight into the questionnaire data, the interview data was assigned to themes which

corresponded to some of the key areas covered by the questionnaire. The broad themes included; decision to seek help, information provision, patient knowledge and understanding, routes to admission, experience of care. Two researchers (LZ and LW) assigned the qualitative data to the above themes.

### **Staff utilisation of the TT system**

Coding criteria was developed to assess overall completion and data quality of the TT forms. Generally, staff used the freetext box at the top of the form to describe the reason for the call and usually gave a written summary of symptoms. They recorded the action taken in a free text box at the bottom of the form. Staff did not always complete the standardised grading assessment fully. The data completeness was coded as;

*TT form used* – Full standardised grading assessment completed, at least for the main symptoms described in the free text boxes.

*TT form partially used* – Standardised grading assessment partially completed, either the grading not specified (i.e. a tick beside the symptom name, rather than circling the red/amber/green), or the grading assessment not completed for all symptoms described in the free text.

*TT form not used* – Symptoms described in the free text boxes but the standardised grading assessment not completed.

*Main symptom not on TT form* – The written summary in the free text boxes was not symptom-related (e.g. medication query), or the symptom was not included in the list (e.g. confusion).

Reported symptoms and severity and advice given were assessed using using crosstabular descriptive statistics (IBM SPSS version 19).

## **RESULTS**

### **Patient experiences during the admission process**



40 patients (13 male, 27 female) completed the RCP audit questionnaire, 26 of whom (8 male, 18 female) participated in the interviews. The majority (33/40, 83%) were on cancer treatment (mainly chemotherapy 25/40, 63%). 7% did not have any current plans for treatment, 7% had treatment planned and 3% had completed their treatment. 37% were 60-69 years, 25% were 50-59 years, 23% were over 70 and 15% were 20-49 years. The common diagnoses were breast cancer (32%), upper and lower gastro-intestinal (27%), followed by lung, haematological, urological and gynaecological cancers (7.5%).

Most patients (91%) felt informed about potential side effects, 100% received written information, 91% felt prepared about the course of action if they had a problem, and 94% followed this advice prior to admission. However, the interviews revealed that sometimes patients found it difficult to apply this information to their own circumstances and could be unsure when to seek help (**for detailed responses see online Appendix 3**).

*'I just thought it was par for the course' (Male, 74, Stomach cancer)*

*'What all the leaflets and booklets don't do is put things into perspective' (Male, 38, Testicular cancer)*

A significant number of patients felt unwell for over 2 days before contacting the hospital (25% waited for 2-3 days, 31% waited for > 4 days). Older patients were more likely to wait longer (37% of patients over 70 years experienced symptoms for > 4 days, compared to 20% of those under 30). The interviews revealed that patients often delayed contacting the hospital to avoid hospital admission if they had family or social plans.

*'I didn't ring over weekend because I had plans and was keen to keep them'*  
*(Female, 40, Breast cancer)*

Patients took a variety of routes to the AOS, 32% drove themselves to the hospital, 30% were referred from an outpatient appointment elsewhere in the hospital, 11% came via ambulance and 5% were referred by their GP. The remaining 22% reported 'other' routes. Of the 30% of patients referred from an outpatient appointment, 60% had felt unwell for 4 days or more, 30% had felt unwell for 2-3 days and the remaining 10% started to feel unwell

the day before. This indicated that patients often delayed contacting the hospital if they had an upcoming appointment, and this was supported by the interview data.

*'I had vomiting all last week from chemo and radiotherapy. From Monday it was very bad but I had a clinic appointment so I just waited until then' (Female, 71, Colorectal)*

Once in the hospital, the majority (65%) were assessed within 30 minutes, 23% were assessed within 30mins-1hour, 9% between 1-2 hours and 3% for more than 2 hours. 3% waited for over 2 hours. 98% of participants reported hospital staff knew about their cancer and treatment, (56% definitely, 42% to some extent); 100% felt confident the staff can deal with their problem (86% definitely, 14% to some extent).

*'It's all been very positive, staff are very competent, I feel like they've seen this lots of times before'. (Female 52, Breast)*

The key concern highlighted by the audit was that 56% of patients felt unwell for over 2 days before contacting the hospital and the variety of routes patients took before arriving to the unit. Therefore, it was felt appropriate as the next step to audit the newly introduced TT system to evaluate its role in streamlining the admission processes.

### **Staff utilisation of the TT system**

#### *Overall use of TT system and data quality*

In March 2011, 119 patients completed a total of 133 TT forms. 69 patients (52%) were admitted following the phone call. The total number of admissions in the month was 266, therefore only 26% came via the TT system. In the June 2013 re-audit, higher use of the TT form was observed with 221 patients completing 264 forms. 129 patients (49%) were subsequently admitted. The total number of admissions in the month was 261, similar to 2011. However, almost half (129/261 49%) of all acute admissions came via the TT system, in comparison to 26% in 2011.

In March 2011, 58% of the TT forms were completed correctly (with indication of the symptom(s) and severity grades), 16% were partially completed. In 13%, the main symptom

was not on the form, and in 13% of cases the TT form was not used as intended and just used to write free text notes. Missing rates for individual symptoms (i.e. not completing the required box Yes/No) were between 5% (pain) and 8% (breathlessness, spinal pain). This rate of missing symptoms was not considered high enough to warrant re-design of the TT form following the audit. In 2013, similar rates of full completion were observed, but the recording of individual symptoms in 2013 was somewhat poorer with missing rates of 16 to 18%.

Table 1 - Overall use and data quality of TT forms

| <b>Overall use of TT forms</b>                  | <b>2011</b>     | <b>2013</b>      |
|---|-----------------|------------------|
| Number of patients staff completed TT forms for | <b>119*</b>     | <b>221*</b>      |
| Total number of TT forms completed              | <b>133</b>      | <b>264</b>       |
| TT forms advising admission                     | 69 (52%)        | 129 (49%)        |
| Admission rate in the audit month               | 266             | 261              |
| Admissions via TT system                        | <b>69 (26%)</b> | <b>129 (49%)</b> |
| <b>Data quality of TT forms</b>                 | <b>N=133</b>    | <b>N=264</b>     |
| TT form used                                    | 58%             | 54%              |
| TT form not used (text notes only)              | 13%             | 11%              |
| TT form partially used                          | <b>16%</b>      | <b>9%</b>        |
| Main symptom not on TT form                     | <b>13%</b>      | <b>26%</b>       |
| Missing data on individual symptoms             | <b>5% - 8%</b>  | <b>16 - 18%</b>  |

\*Differences between 2011 and 2013 are in bold

### *Patient characteristics*

In March 2011, just over half (52%) of patients were male and 48% were female. 57% were over 60, the common diagnoses were colorectal cancer 16%, breast 16%, upper GI 13%, haematological 13%, lung 10% and gynaecological 6%. 68% were on chemotherapy, 35% of whom were in the first 7 days post treatment.

Patient characteristics in June 2013 were broadly similar, but with a larger proportion of female patients, smaller proportion on chemotherapy and 28% of patients not on active treatment (**Table 2**).

Table 2 - Patient characteristics

| <b>Patient Characteristics</b>      | <b>2011</b>     | <b>2013</b>   |
|-------------------------------------|-----------------|---------------|
| <b>Gender</b>                       | <b>N=119</b>    | <b>N=221</b>  |
| Male                                | <b>52%</b>      | <b>39%</b>    |
| Female                              | <b>48%</b>      | <b>61%</b>    |
| <b>Age (Median, Range)</b>          | (61.5, 22 - 86) | (61, 19 - 95) |
| <b>Diagnosis</b>                    |                 |               |
| Colorectal                          | 16%             | 11%           |
| Breast                              | 16%             | 15%           |
| Upper GI                            | 13%             | 10%           |
| Haematology                         | 13%             | 9%            |
| Lung                                | 10%             | 11%           |
| Gynae                               | 6%              | 14%           |
| Other                               | 23%             | 29%           |
| Missing                             | 3%              | 1%            |
| <b>Treatment</b>                    |                 |               |
| Chemotherapy                        | <b>68%</b>      | <b>54%</b>    |
| Radiotherapy                        | 3%              | 5%            |
| Biological therapy                  | 3%              | 9%            |
| Hormone therapy                     | 1%              | 2%            |
| Surgery                             | 2%              | 1%            |
| Other                               | 0%              | 1%            |
| No treatment                        | <b>5%</b>       | <b>28%</b>    |
| Missing                             | 19%             | 1%            |
| <b>Days since last chemotherapy</b> |                 |               |
| 0 – 7 days                          | 35%             | 29%           |
| 7 – 14 days                         | 16%             | 11%           |
| 14 + days                           | 7%              | 10%           |
| Oral chemotherapy                   | 5%              | 4%            |
| Not on chemo                        | <b>26%</b>      | <b>45%</b>    |
| Missing                             | <b>12%</b>      | <b>1%</b>     |

### *Reported symptoms*

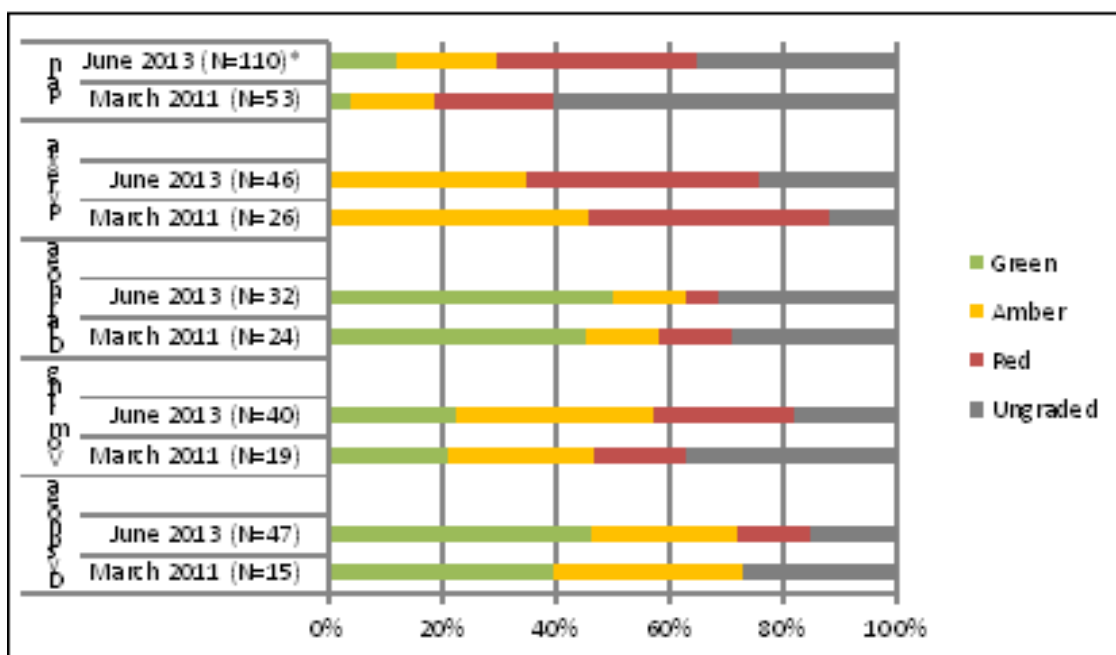
The most commonly reported symptoms in the March 2011 audit were pain (42%), pyrexia/rigors/infection (27% combined), diarrhoea (19%), vomiting (15%) and dyspnoea (12%). For 51% of calls received, patients reported multiple symptoms. Pain was the symptom most commonly reported symptom on its own and in combination with other

problems. The most commonly reported issues which were not listed on the TT form were queries about medications/devices (3 calls, 15%) and confusion (3 calls, 15%).

29% of the calls were for Red level symptoms (Grade 3-4), 23% were graded as Amber and only 5% as Green (mild) symptoms. The remaining 43% of forms were either incorrectly used or the main symptom was not on the form.

In June 2013, commonly reported symptoms and their severity were similar to 2011 (**Figure 1**). In significantly more cases (26%) the main symptom/problem was not on the TT form, likely due to higher clinical variability as the TT form was used in twice as many patients. These problems were, as in the first audit, questions about medications (12 calls, 16%) and from the symptoms – confusion (6 calls, 8%). The audit recommended that ‘confusion’ and ‘queries about medications’ be added to the TT form.

**Figure 1 - Distribution of grading for most commonly reported symptoms**



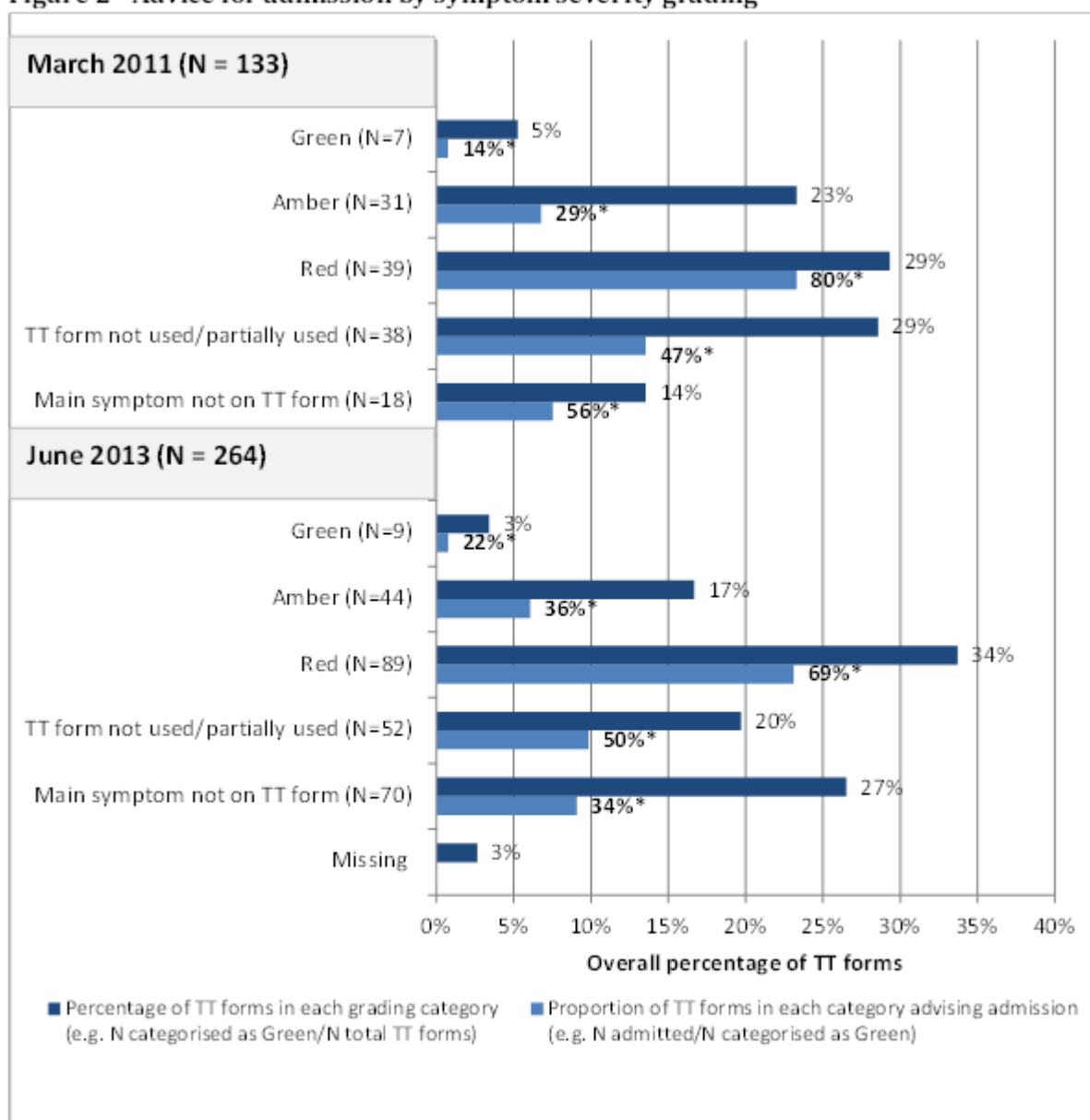
\*N=number of TT forms reporting the symptom (i.e. not left blank)

Advice given (Table 3) (Figure 2)

Table 3- Advice given

| Advice given    | 2011         | 2013         |
|-----------------|--------------|--------------|
|                 | <b>N=133</b> | <b>N=264</b> |
| For admission   | 52%          | 49%          |
| Go to A&E       | 4%           | 6%           |
| Go to GP        | 11%          | 14%          |
| Self-management | <b>30%</b>   | <b>17%</b>   |
| Other           | <b>3%</b>    | <b>11%</b>   |
| Missing         | 0%           | 3%           |

Figure 2 - Advice for admission by symptom severity grading



\*Refers to the percentage of forms advising admission in each grading category. E.g. 39 forms in red category, 31 advising admission. 31/39=80%

In March 2011, half of the patients (52%) were advised to attend the unit for assessment, 4% to attend A&E, 11% to call/visit the GP, 30% were encouraged to self-manage the symptoms, 3% received other advice (call the district nurse, the Macmillan nurse, the radiotherapy ward).

As expected the severity of the symptoms was related to the advice: 80% of the patients with red symptoms were admitted, 29% of the patients with amber and only 1 patient (14%) with green symptoms. The admission rate for the symptoms not on the TT form was 56% with 30% of these patients admitted with confusion, 20% with dizziness and the remainder with various other problems (e.g. double vision). Notably 47% of patients with incorrectly completed TT forms were admitted, which suggests that the TT forms were not always utilised fully even when serious symptoms were present.

43% of patients with green symptoms, 52% with amber symptoms and 15% with red symptoms were advised to self-manage. The admission rate via the TT system was similar in June 2013 at 49%, but a smaller proportion of patients were encouraged to self-manage (17%), whereas more were directed to their GP, A&E or given a variety of other advice. Symptom severity was related to advice as in 2011.

## **DISCUSSION**

Our audit provided evidence of successful reconfiguration of the AOS and subsequent service uptake. The 2011 patient questionnaires and interviews revealed high satisfaction rates with the streamlined system. Patients reported that hospital staff knew about their cancer and treatment and felt confident that staff could deal with their problem. Patients were also well informed about potential side-effects of their treatment and how to access the hospital.

Although around a third of patients contacted the hospital on the first day they experienced symptoms, over 50%, predominantly older patients, had symptoms for up to a week before they sought advice. This finding is similar to the RCP report.[8] Our data suggests that the

delay in seeking medical help appears to be due to patient-related factors rather than lack of information. Patients were keen to keep social plans, avoid hospital admission or had an upcoming outpatient appointment. .

The audit also provided evidence of successful implementation of the TT system, with the main objectives being met. The system aimed to support nurse decision-making by classifying side-effects into mild (Green), moderate (Amber) or severe (Red). Over 80% of patients with serious Red symptoms were admitted and over 30% of those with moderate (Amber symptoms). Overall about 50% of patients who used the TT system were admitted. These figures are remarkably similar to those reported in the evaluation of UKONS Toolkit, confirming the value and generalizability of this approach.[11]

The TT system also demonstrated streamlined procedures for acute admissions. In 2011, 26% of acute admissions were via TT system whereas in 2013, 49% of the admissions came via this system. This admission rate is similar to other studies.[7] A separate, unpublished audit of length of hospital stay at the same site demonstrated that a further benefit of the reconfiguration was a reduction of days in hospital from an average of 9 days to 6 days. The TT system also aimed to standardise the documentation of patient's symptoms and AEs. The quality of TT form completion in 2011 was comparable to that reported by UKONS (70%), but deteriorated over time. This may be partially due to increased number of phone calls with wider range of symptoms that are not fully covered by the form. We found that the most frequent problems recorded which were not on the TT form were confusion and medications/devices queries. Neurological events and medication queries were among the top 5 diagnoses leading to emergency cancer admissions, reported by M.D. Anderson Cancer Center.[1]

This audit has **limitations**. We only interviewed patients in 2011 and were unable to repeat the interviews due to limited resources in 2013. We only interviewed patients who were admitted and not those who received telephone advice, or attended the unit for assessment



and were subsequently discharged. In addition, we were unable to interview admitted patients who were severely unwell. Exploring the experiences of those patients would further understanding of how effective the service is across the board. This audit was not a full evaluation of the service from a point of view of all stakeholders. It could be strengthened by interviewing AOS staff to understand their views of TT system.[11] Although a standardised approach to training in use of the form was adopted by the trust there could have been some variation in which was beyond our control.

### *Recommendations*

Our audit has emphasised the need to educate patients on the importance of early intervention for symptoms. However, an appreciation of the life context within which cancer patients are making decisions about symptom management is likely to be helpful in designing strategies to enhance timely reporting.

We also recommend that confusion and medication queries be added to the TT form. In the majority of cases where completion of the TT form was poor, it appeared that the staff did not use the form as a decision support tool, but just to take notes. This may be a result of both the time pressure due to increased number of phone calls, and to new staff joining the unit. On-going staff training should be provided, emphasising the importance of full completion of the forms to allow their use as a decision-support tool.

A proportion of patients reported mild symptoms and were advised to self-manage. This finding indicates that a robust targeted self-management programme could be one intervention strategy which could afford patients autonomy whilst maintaining safety by providing tailored, automated self-management advice to patients with low level symptoms.

### *Conclusions*

In summary, this single cancer centre audit provides data supporting the successful implementation of AOS, resulting in streamlining of admissions and good patient

experiences. Electronic solutions to reporting of symptoms by both patients and hospital staff should be encouraged to make the process more efficient, safe and cost-effective.

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# ONLINE APPENDICES

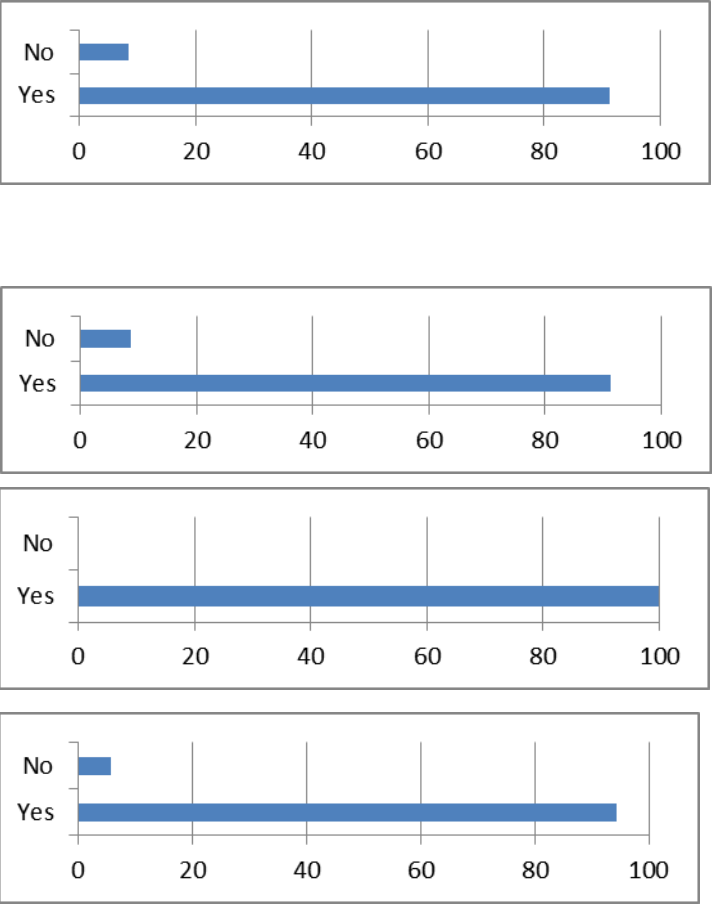
## Online appendix 1 – Telephone Triage form

| St James's Institute Oncology   |             | Acute Oncology Triage Assessment   |   | The Leeds Teaching Hospitals NHS Trust  |  |                                       |
|---|-------------|--|---|---|--|---------------------------------------|
| Leave completed forms on ward for scanning into PPM                             |             |  |   |   |  |                                       |
| Date:   | Tel:        | Time:  |   | Colour codes are intended to give guidance and should not replace clinical judgement. Use the linked management flow charts as a guide for identified problems. |  |                                       |
| Name:   |             |  |   |   |  |                                       |
| Hospital number   | DOB:        |  | Advice over telephone. Ask patient to phone back if still worried                                 | Consider if face to face assessment in OPD or Ward 95 is needed   | Requires urgent medical assessment on Ward 95  |                                       |
| Diagnosis   | Consultant: |  |   |   |  |                                       |
| Chemo / Other drug regime   |             |  |   |   |  |                                       |
| Days since last treatment: .....  | days        | Is patient on a clinical trial?  | YES / NO  | ** Is patient taking capecitabine? - see capecitabine management chart**  |  |                                       |
| Circle interval to assess risk:   |             | 0-6  | 7 - 14<br>Neutrophil nadir  | 14+   | not on chemo   |                                       |
| Problem expressed by patient:   |             |  |   |   |  |                                       |
| Symptom Assessment  |             | Yes or No  |   |   |  |                                       |
|   |             | If yes, circle appropriate level   |   |   |  |                                       |
| Pyrexia   |             | 37-38  | 38 > 1 hour   | >38.5   | See Febrile Neutropenia Flowchart  |                                       |
| Rigors  |             | Yes  |   |   |  |                                       |
| Other signs of infection? cough, dysuria, sore throat, broken skin, rash, other |             | Yes  | Plus feeling unwell   |   | Caution! Temperature and local signs such as inflammation and pus may not be present in profound neutropenia |                                       |
| Hickman line/ Portacath/ PICC line sore, red, discharge                         |             | Mild redness around site. Slight discharge. No tracking  | Redness, discharge tracking up the line. Presence of signs listed above                           |   | See central line troubleshooting flowchart   |                                       |
| Bleeding  |             | Minor bleeding: slight nosebleed, haemoptysis, haematuria etc  | Major bleeding  |   | See Bleeding/bruising Flowchart<br>See Haemoptysis Flowchart   |                                       |
| Nausea  |             | Slight, no alteration to eating  | Oral intake decreased. No dehydration   | Inadequate intake. Dehydration or at risk   | See Nausea & Vomiting Flowchart  |                                       |
| Vomiting  |             | 1 episode in 24 hrs  | 2-5 episodes in 24 hrs  | > 6 episodes in 24 hrs  |  |                                       |
| Diarrhoea   |             | < 4 stools per day over baseline; mild increase in ostomy output over baseline   | 4-6 stools per day over baseline. Moderate ostomy output over baseline. Not interfering with ADL. | > 7 stools per day over baseline; incontinence; severe increase in ostomy output; interfering with ADL.   | See Diarrhoea Flowchart  |                                       |
| Sore mouth  |             | Mild discomfort  | Discomfort requiring topical analgesics, able to eat & drink                                      | Severe discomfort. Unable to eat and drink  | See Mucositis Flowchart  |                                       |
| Sore hands/feet   |             | Mild, no cracking, blistering, pain  | Cracks, blisters, pain but not interfering with ADL   | Severe blistering and pain, unable to use feet/hands  | See Palmar/plantar Flowchart   |                                       |
| Constipation  |             | Mild requiring dietary modification, start laxatives   | Moderate requiring increased laxatives / enema  | May have impaction or obstruction   | See Constipation Flowchart   |                                       |
| Breathlessness  |             | On exertion only   | Breathlessness with minimal activity  | Breathlessness at rest, accompanied by chest pain   | See Breathlessness Flowchart   |                                       |
| Spinal pain, limb weakness, sensory loss, paraesthesia                          |             | Spinal cord compression symptoms: spinal pain, limb weakness, sensory loss, paraesthesia, difficulty walking, bladder or bowel dysfunction |   |   |  | See Spinal Cord Compression Flowchart |
| Pain  |             | Severity of pain on 0-10 scale:  | Site of pain:   | Current analgesia:  | See Pain Flowchart   |                                       |
| Other problem: (describe)   |             |  |   |   |  |                                       |
| Name of SpR / Consultant discussed with:  |             |  |   |   |  |                                       |
| Advice Given/ Action taken. Followup required? Yes / No                         |             |  |   |   |  |                                       |
| Continue overleaf if needed   |             |  |   |   |  |                                       |
| Name of person completing form:   |             |  |   |   |  |                                       |

## Online appendix 2 – Patient interview schedule

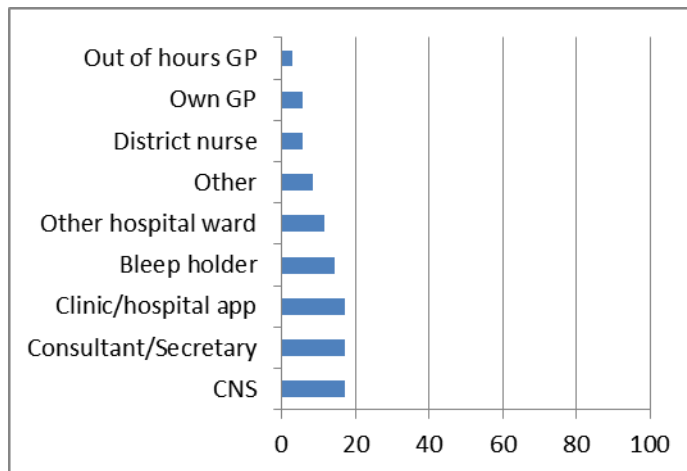
| <b>Number</b> | <b>Question</b>   |
|---------------|---|
| 1             | Please could you tell me a bit about the problem that led to your admission?                      |
| 2             | How long did the problem exist before you sought help?  |
| 3             | Did you know who to contact for help/advice?  |
| 4             | When did you receive information about who to contact?  |
| 5             | Who provided the information?   |
| 6             | Was it written information/given verbally/both?   |
| 7             | Did the information distinguish between what you should do if you had a problem during the night? |
| 8             | What happened when you contacted (insert relevant contact from Q3)?                               |
| 9             | What advice were you given?   |
| 10            | Did you contact your GP? Did you consider contacting your GP at any time?                         |

Online appendix 3 - Results from RCP questionnaire and patient interview

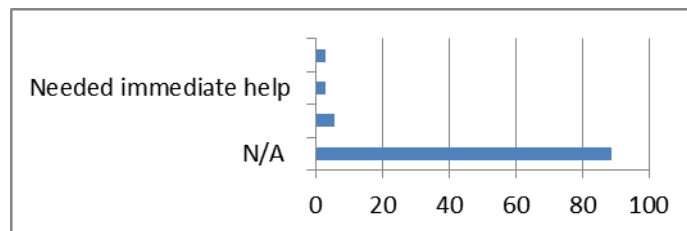
| Information provision prior to admission   | Responses (%) (N=40)  | Supporting quotes   |         |        |  |    |    |   |    |    |  |     |   |                      |    |    |   |
|--|---|---|---------|--------|--|----|----|---|----|----|--|-----|---|----------------------|----|----|---|
| <p>Have you been told about any problems that you could develop which are related to side effects of any cancer treatment you have had?</p> <p>Did you feel prepared about what to do and who to contact if you had a problem?</p> <p>Prior to this hospital admission, were you given information on what to do if you became unwell?</p> |  <table border="1" data-bbox="488 347 1200 1257"> <caption>Response Data for Information Provision</caption> <thead> <tr> <th>Question</th> <th>Yes (%)</th> <th>No (%)</th> </tr> </thead> <tbody> <tr> <td>Have you been told about any problems that you could develop which are related to side effects of any cancer treatment you have had?</td> <td>90</td> <td>10</td> </tr> <tr> <td>Did you feel prepared about what to do and who to contact if you had a problem?</td> <td>90</td> <td>10</td> </tr> <tr> <td>Prior to this hospital admission, were you given information on what to do if you became unwell?</td> <td>100</td> <td>0</td> </tr> <tr> <td>(Unlabeled question)</td> <td>90</td> <td>10</td> </tr> </tbody> </table> | Question  | Yes (%) | No (%) | Have you been told about any problems that you could develop which are related to side effects of any cancer treatment you have had? | 90 | 10 | Did you feel prepared about what to do and who to contact if you had a problem? | 90 | 10 | Prior to this hospital admission, were you given information on what to do if you became unwell? | 100 | 0 | (Unlabeled question) | 90 | 10 | <p><b>The majority of patients stated they had sufficient information on:</b></p> <p><b>Side effects</b><br/> <i>'At the initial consultation, pre-chemo, was given sheets of information'</i> Female, 55 (Colorectal)</p> <p><i>'Oncology nurse emphasised high temperature being important'</i> Female, 52 (Breast)</p> <p><b>Contact details</b><br/> <i>'Given number to ring before started treatment on card'</i>. Male. 38 (Testicular)</p> <p><i>'I go to St. Gemma's on Wednesdays so I was unsure whether to go to there for advice or the GPs or to ring here'</i> Female, 63 (Breast)</p> <p><b>What to do if unwell</b><br/> <i>'Right at beginning of treatment there was a card with everything highlighted - different person to ring during day and night'</i> Female, 41(Breast)</p> <p><i>'Card details in wallet and big book. Verified verbally'</i>. Male, 74 (Gastric)</p> <p><i>'What all the leaflets and booklets don't do is put things into perspective'</i>. Male. 38 (Testicular)</p> |
| Question   | Yes (%)   | No (%)  |         |        |  |    |    |   |    |    |  |     |   |                      |    |    |   |
| Have you been told about any problems that you could develop which are related to side effects of any cancer treatment you have had?   | 90  | 10  |         |        |  |    |    |   |    |    |  |     |   |                      |    |    |   |
| Did you feel prepared about what to do and who to contact if you had a problem?  | 90  | 10  |         |        |  |    |    |   |    |    |  |     |   |                      |    |    |   |
| Prior to this hospital admission, were you given information on what to do if you became unwell?   | 100   | 0   |         |        |  |    |    |   |    |    |  |     |   |                      |    |    |   |
| (Unlabeled question)   | 90  | 10  |         |        |  |    |    |   |    |    |  |     |   |                      |    |    |   |
| <p><b>Experiences prior to admission</b></p>   |   |   |         |        |  |    |    |   |    |    |  |     |   |                      |    |    |   |
| <p>On this particular</p>  |   | <p><b>The majority of patients said they followed the given</b></p> |         |        |  |    |    |   |    |    |  |     |   |                      |    |    |   |

occasion, did you follow it?

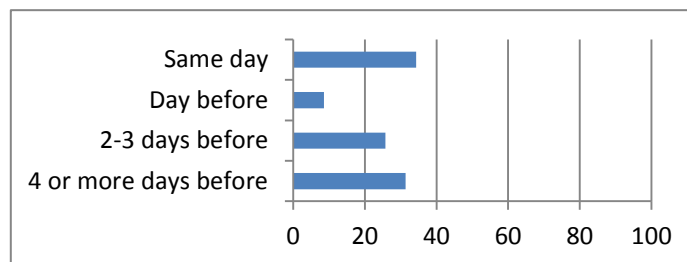
Did you contact anyone for advice or help before attending the hospital?



If you did not make contact with anyone prior to attending the hospital, why was this?



When did you first start to feel unwell before you went to hospital?



**information on what to do if they were unwell :**

*'I felt hot. My wife took my temperature which was quite high. My wife called up and they told me to come in. I was feeling generally unwell too'* Male, 70 (Lung)

**However, others did not ring immediately and chose to wait for the next OPD appointment:**

*'Yes, knew would be seeing Dr\* in clinic and he would sort me out'* Female, 59 (Ovarian)

*'Didn't consider ringing because knew about outpatient appointment ...'* Female, 59 (Breast)

*'Came to see Mr \* in outpatients. He wrote plan for stay. (IV fluid and IV antiemetic and admitted to ward'* Female 65 (Oesophageal)

**Although they are encouraged to make contact via the telephone numbers provided; sometimes other means of admission /advice were taken**

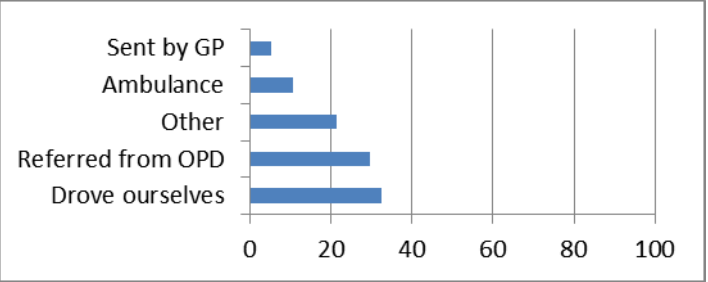
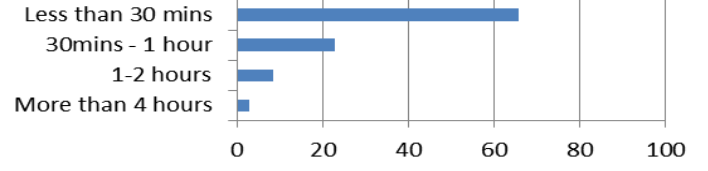
*'District nurse got advice to phone ambulance and come straight to ward 96'* Female, 63 (Breast)

*'Yes but he wasn't able to provide IV fluids etc so needed admitting'* Female, 65 (Oesophageal)

*'Had no appointments due, so contacted breast care nurse to ask her advice, she arranged clinic appointment, scan, x-rays and its gone on from there'* Female, 58 (Breast)

**Patients seem aware of the limitations of staff particularly in primary care:**

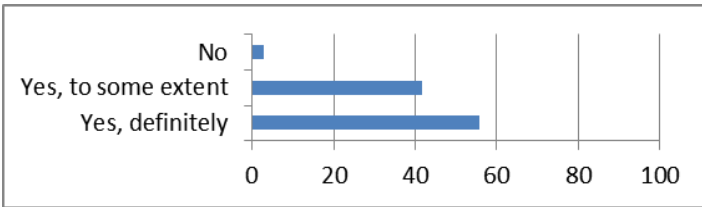
*'My GP doesn't know enough about this type of specialist thing- I always try and speak to someone at the hospital if possible.'* Female, 40, (Breast)

| <p>How were you admitted to hospital?</p>  |  <table border="1"> <caption>Admission Methods</caption> <thead> <tr> <th>Method</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Sent by GP</td> <td>~5%</td> </tr> <tr> <td>Ambulance</td> <td>~10%</td> </tr> <tr> <td>Other</td> <td>~20%</td> </tr> <tr> <td>Referred from OPD</td> <td>~30%</td> </tr> <tr> <td>Drove ourselves</td> <td>~35%</td> </tr> </tbody> </table> | Method | Percentage | Sent by GP        | ~5%  | Ambulance       | ~10% | Other     | ~20% | Referred from OPD | ~30% | Drove ourselves   | ~35% | <p><i>'No don't contact GP about anything cancer related, they don't know enough about it.'</i> Female, 59 (Ovarian)</p> <p><b>A quarter of the patients waited 2-3 days before contacting the hospital, and 31% waited for over 4 days, despite the specific advice. Some reasons were outlined during the interviews</b></p> <p><i>'Since Sat (3 days). Didn't ring over weekend because had plans and was keen to keep them. Phoned this morning because of nose bleeds/cold/headache this morning and rash on head'</i> Female, 40 (Breast cancer)</p> <p><i>'I had vomiting all last week from chemo and radiotherapy. From Monday it was very bad but I had a clinic appointment so I just waited until then'</i> Female, 71 (Colorectal)</p> <p><i>'Approximately 1 week, came to routine OP appointment'</i> Female, 59 (Breast)</p> <p><i>'5 days and had been getting increasingly worse '</i> Female, 66 (Bowel, endometrial)</p> <p><i>Yes, coming in earlier would have been better because now very dehydrated - Just been struggling through.</i> Male, 38 (Testicular)</p> <p><i>Had diarrhoea for 3 days, rang bleep holder, husband drove me in'. Female, 40 (Melanoma)</i></p> |
|--|--|--------|------------|-------------------|------|-----------------|------|-----------|------|-------------------|------|---|------|---|
| Method   | Percentage   |        |            |                   |      |                 |      |           |      |                   |      |   |      |   |
| Sent by GP   | ~5%  |        |            |                   |      |                 |      |           |      |                   |      |   |      |   |
| Ambulance  | ~10%   |        |            |                   |      |                 |      |           |      |                   |      |   |      |   |
| Other  | ~20%   |        |            |                   |      |                 |      |           |      |                   |      |   |      |   |
| Referred from OPD  | ~30%   |        |            |                   |      |                 |      |           |      |                   |      |   |      |   |
| Drove ourselves  | ~35%   |        |            |                   |      |                 |      |           |      |                   |      |   |      |   |
| <p><b>Experience of care on the AOS</b></p>  |  |        |            |                   |      |                 |      |           |      |                   |      |   |      |   |
| <p>How long was it from arrival at the hospital before you were assessed by a doctor or a nurse?</p> |  <table border="1"> <caption>Assessment Times</caption> <thead> <tr> <th>Time</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Less than 30 mins</td> <td>~65%</td> </tr> <tr> <td>30mins - 1 hour</td> <td>~20%</td> </tr> <tr> <td>1-2 hours</td> <td>~10%</td> </tr> <tr> <td>More than 4 hours</td> <td>~5%</td> </tr> </tbody> </table>                                   | Time   | Percentage | Less than 30 mins | ~65% | 30mins - 1 hour | ~20% | 1-2 hours | ~10% | More than 4 hours | ~5%  | <p><b>The majority of patients (65%) were assessed in less than 30 minutes.</b></p> <p><i>'... got a bed quickly, got to hospital quickly and was seen quickly'</i> Male, 72 (Pancreatic)</p> <p><i>'... this time didn't need to wait a long time for a bed, sometimes</i></p> |      |   |
| Time   | Percentage   |        |            |                   |      |                 |      |           |      |                   |      |   |      |   |
| Less than 30 mins  | ~65%   |        |            |                   |      |                 |      |           |      |                   |      |   |      |   |
| 30mins - 1 hour  | ~20%   |        |            |                   |      |                 |      |           |      |                   |      |   |      |   |
| 1-2 hours  | ~10%   |        |            |                   |      |                 |      |           |      |                   |      |   |      |   |
| More than 4 hours  | ~5%  |        |            |                   |      |                 |      |           |      |                   |      |   |      |   |



Did the staff seem to know about you and your cancer and the treatment you had been having?

Did you feel confident in the staffs ability to deal effectively and quickly with your problem?



*before have had to wait for several hours'. Female, 59 (Ovarian)*

*'It's all been very positive, staff are very competent, feel like they've seen this lots of times before'. Female 52 (Breast)*

*'I can't think how they could have made it any better'. Female, 52 (Breast)*