

Citation:

Warrington, L and Holch, P and Kenyon, L and Hector, C and Kozlowska, K and Kenny, AM and Ziegler, L and Velikova, G (2016) An audit of acute oncology services: patient experiences of admission procedures and staff utilisation of a new telephone triage system. Support Care Cancer. ISSN 1433-7339 DOI: https://doi.org/10.1007/s00520-016-3370-4

Link to Leeds Beckett Repository record: https://eprints.leedsbeckett.ac.uk/id/eprint/3098/

Document Version: Article (Accepted Version)

The aim of the Leeds Beckett Repository is to provide open access to our research, as required by funder policies and permitted by publishers and copyright law.

The Leeds Beckett repository holds a wide range of publications, each of which has been checked for copyright and the relevant embargo period has been applied by the Research Services team.

We operate on a standard take-down policy. If you are the author or publisher of an output and you would like it removed from the repository, please contact us and we will investigate on a case-by-case basis.

Each thesis in the repository has been cleared where necessary by the author for third party copyright. If you would like a thesis to be removed from the repository or believe there is an issue with copyright, please contact us on openaccess@leedsbeckett.ac.uk and we will investigate on a case-by-case basis.

An audit of acute oncology services: Patient experiences of

admission procedures and staff utilisation of a new telephone

triage system

Lorraine Warrington a\*, Patricia Holch a, Lucille Kenyon a, Ceri Hector a, Krystina Kozlowska b,

Anne Marie Kenny b, Lucy Ziegler a&, Galina Velikova a&.

<sup>a</sup> University of Leeds, Leeds Institute of Cancer and Pathology, Section of Patient Centred Outcomes Research,

Beckett Street, Leeds, LS9 7TF, United Kingdom

<sup>b</sup> St James's Institute of Oncology, Leeds Teaching Hospitals NHS Trust. Beckett Street, Leeds, LS9 7TF, United

Kingdom

& Joint senior authors

\*Corresponding author: Lorraine Warrington

E: I.warrington@leeds.ac.uk

T: +44 113 2067548

Leeds Institute of Cancer Studies and Pathology

University of Leeds

Bexley Wing (Level 3)

St James's Hospital

**Beckett Street** 

Leeds LS9 7TF, UK

Conflicts of interest: none to declare

**Keywords:** Oncology, acute admissions, adverse events, telephone triage, supportive care

1

## **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 cancerrelated 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]

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

# **Clinical setting**

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:

- 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, selfmanagement) 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 consequtively 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 Asessment 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 statisitics (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 utilistation 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 utilistation 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

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

<sup>\*</sup>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

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

# 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.

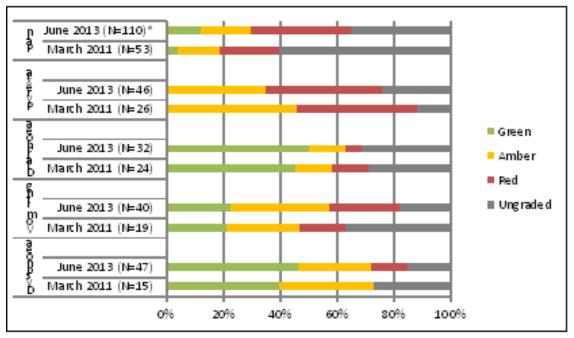


Figure 1 - Distribution of grading for most commonly reported symptoms

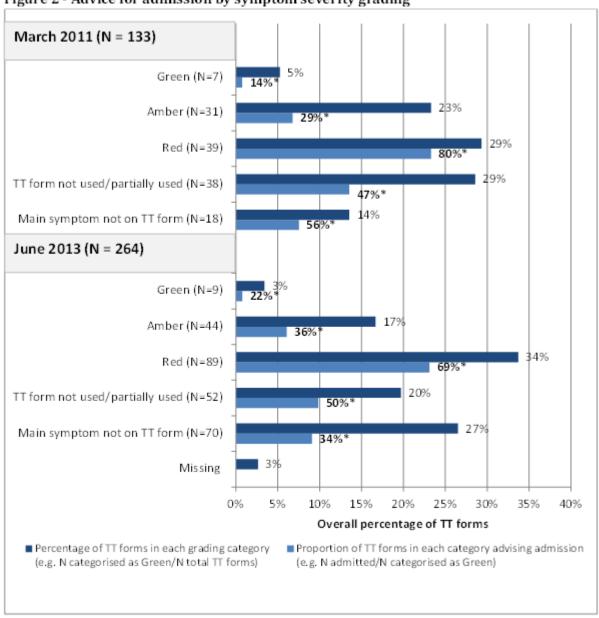
<sup>\*</sup>N=number of TT forms reporting the symptom (i.e. not left blank)

# Advice given (Table 3) (Figure 2)

Table 3- Advice given

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

Figure 2 - Advice for admission by symptom severity grading



<sup>\*</sup>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.

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.

Acknowledgements: The authors would like to thank Dr. Geoff Hall, Dr. Alison Young and all AOS staff for their co-operation and support.

This work was carried out as part of the eRAPID Development Grant RP-DG-1209-10031; ISCTRN trial number CCT-NAPN-21338, funded by the National Institute for Health Research (NIHR).

#### REFERENCES

- 1. Delgado-Guay MO, Kim YJ, Shin SH, Chisholm G, Williams J, Allo J, Bruera E (2014) Avoidable and Unavoidable Visits to the Emergency Department Among Patients With Advanced Cancer Receiving Outpatient Palliative Care Journal of pain and symptom management
- 2. Marshall E, Young A, Clark P, Selby P (2014) Problem Solving in Acute Oncology. Clinical Publishing, Oxford
- 3. National Audit Office (2010) Delivering the Cancer Reform Strategy. In: Editor (ed)^(eds) Book Delivering the Cancer Reform Strategy, City.
- 4. National Cancer Action Team (2011) National Cancer Peer Review Programme Manual for Cancer Services: Chemotherapy Measures. In: Editor (ed)^(eds) Book National Cancer Peer Review Programme Manual for Cancer Services: Chemotherapy Measures, City.
- 5. National Chemotherapy Advisory Group ftDoH (2009) Chemotherapy Services in England: Ensuring quality and safety. In: Editor (ed)^(eds) Book Chemotherapy Services in England: Ensuring quality and safety, City.
- 6. National Confidential Enquiry into Patient Outcome and Death (2008) For better, for worse? A review of the care of patients who died within 30 days of receiving systemic anti-cancer therapy. In: Editor (ed)^(eds) Book For better, for worse? A review of the care of patients who died within 30 days of receiving systemic anti-cancer therapy, City.
- 7. Nirenberg A, Mulhearn L, Lin S, Larson E (2004) Emergency department waiting times for patients with cancer with febrile neutropenia: a pilot study Oncol Nurs Forum 31: 711-715
- 8. Royal College of Physicians and Royal College of Radiologists (2012) Cancer patients in crisis: responding to urgent needs. Report of a working party. In: Editor (ed)^(eds) Book Cancer patients in crisis: responding to urgent needs. Report of a working party, City.
- 9. Swenson KK, Rose MA, Ritz L, Murray CL, Adlis SA (1995) Recognition and evaluation of oncology-related symptoms in the emergency department Ann Emerg Med 26: 12-17
- 10. Tsai SC, Liu LN, Tang ST, Chen JC, Chen ML (2010) Cancer pain as the presenting problem in emergency departments: incidence and related factors Support Care Cancer 18: 57-65
- 11. UK Oncology Nursing Society (2010) Oncology/Haemotology 24 hour triage rapid assessment and access toolkit evaluation. In: Editor (ed)^(eds) Book Oncology/Haemotology 24 hour triage rapid assessment and access toolkit evaluation, City.

# **ONLINE APPENDICES**

# Online appendix 1 – Telephone Triage form

St James's Institute Oncology	Oncology Triage Assessment			The Leeds Teaching Hospitals NES			
				on ward for scanning into	on ward for scanning into PPM		
Date:	Tel:		Ti	Colour codes are intended to give guidance and sh		nce 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.	Consider if face to face assessment in	Requires urgent	
Diagnosis			Consultant:	Ask patient to phone back if still womed	OPD or Ward 95 is medical assessment needed Ward 95		
Chemo / Other drug regime							
Days since last treatment:	days	Is patient on a clinical trial?	YES / NO	** Is patient taking capecitat	ine? . see canacitahine	management chart**	
Circle interval to asse	es risk:	0-6	7 - 14 Neutrophil nadir	14+		n chemo	
Problem expressed by	y patient:						
Assessment	Yes or No		If yes, circle appropriate	level	7		
Pyrexia		37-38	38 > 1 hour	>38.5		See Febrile	
Rigors		Yes			-	Neutropenia Flowchart	
Other signs of infection?: cough, dysuria, sore throat, broken skin, rash, other		Yes	Plus feeling unwell	-	inflammation and pu	e and local signs such as is may not be present in 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		$\rightarrow$	See central line troubleshooting flowchart	
Bleeding		Minor bleeding; slight nosebleed, haemoptysis, haematuria etc	Major bleeding	$\rightarrow$	See Bleeding/bruising Flowchart	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		Vocating From Chart	
Diamhoea		< 4 stools per day over baseline; mild increase in oatomy output over baseline	4-6 stools per day over baseline. Moderate ostomy output over baseline. Not interfereing with ADL.	> 7 stools per day over baseline; incontinence; severe increase in ostoniy output. Interfering with ADL		See Diarrhoea Flowchart	
Sore mouth		Mild discomfort	Discomfort requiring topical analgesics, able to eat & drink	Severe discomfort. Unable t eat and drink	·	See Mucositis Flowchart	
Sore hands/feet		Mild, no cracking, bistering, pain	Cracks, bilsters, pain but not interfering with ADL	Severe bilstering and pain, unable to use feet/hands	$\rightarrow$	See Palmaniplantar 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	Breathleseness at rest, accompanied by chest pain	-	See Breathlessness Flowchart	
Spinal pain, limb weakness, sensory loss, paraesthesia		Spinal cord compression symptoms: spinal pain, limb weakness, se paraesthesia, difficulty walking, bladder or bowel dysfuncti			$\rightarrow$	See Spinal Cord Compression Flowchart	
Pain		Severity of pain on 0 -10 scale:	Site of pain:	Current analgesia:	<b>→</b>	See Pain Flowchart	
Other problem: (describe)							
Name of SpR / Consu	Atant discusses	d with:					
Advice Given/ Action taken. Followup required? Yes / No						inua annada e e	
Name of person completing form:					Cont	inue overleaf if needed	

# Online appendix 2 – Patient interview schedule

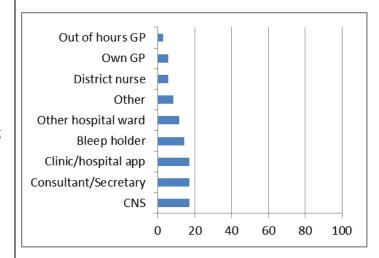
Number	Question
1	Please could you tell me a bit about the problem that led to your admission?
2	How long did the problem exist before you sought help?
3	Did you know who to contact for help/advice?
4	When did you receive information about who to contact?
5	Who provided the information?
6	Was it written 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	Responses (%) (N=40)			Supporting quotes	
prior to admission					
Have you been told about any problems that you could	No Yes			The majority of patients stated they had sufficient information on:	
develop which are related to side effects of any cancer treatment you have	0 20	40 60	80 100	Side effects 'At the initial consultation, pre-chemo, was given sheets of information' Female, 55 (Colorectal)	
had?  Did you feel prepared				'Oncology nurse emphasised high temperature being important' Female, 52 (Breast)	
about what to do and who to contact if you had a problem?	No Yes 0 20	40 60	80 100	Contact details 'Given number to ring before started treatment on card'. Male. 38 (Testicular)	
Prior to this hospital admission, were you given information on what to do if you became unwell?	No Yes 0 20	40 60	80 100	'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' Female, 63 (Breast)  What to do if unwell  'Right at beginning of treatment there was a card with everything highlighted - different person to ring during day and night'  Female, 41(Breast)	
	No Yes			'Card details in wallet and big book. Verified verbally'. Male, 74 (Gastric)	
	0 20	40 60	80 100	What all the leaflets and booklets don't do is put things into perspective'. Male. 38 (Testicular)	
Experiences prior to admission					
On this particular				The majority of patients said they followed the given	

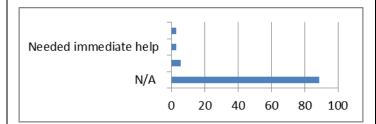
occasion, did you follow it?

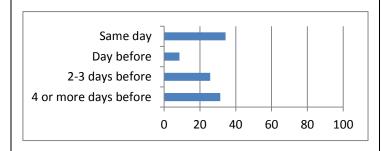
Did you contact anyone for advice or help before attending the hospital?



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 (Oesophogeal)

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

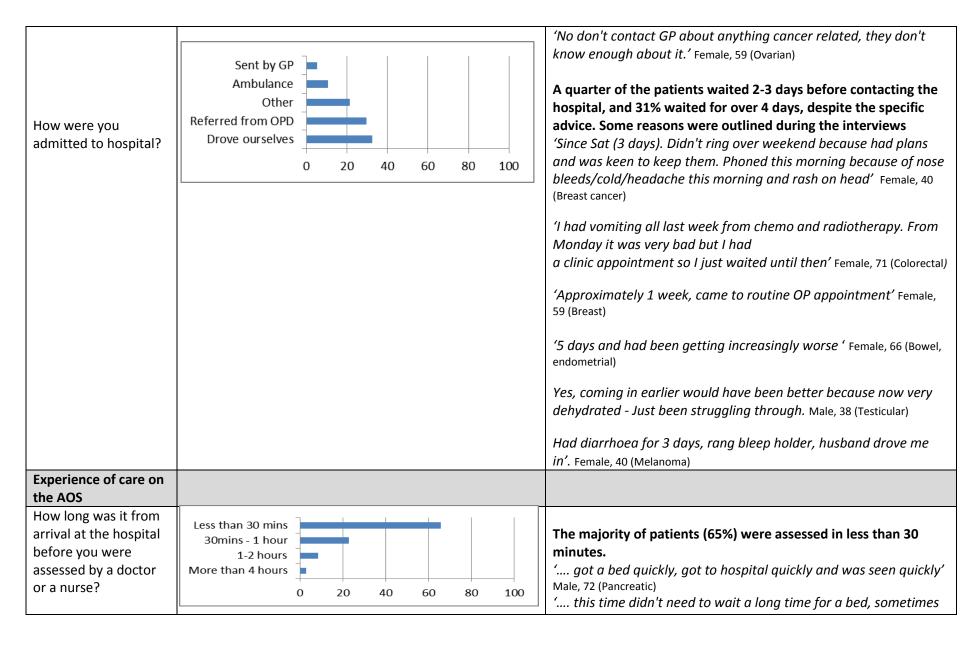
'District nurse got advice to phone ambulance and come straight to ward 96' Female, 63 (Breast)

'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)

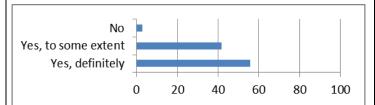
Patients seem aware of the limitations of staff particularly in primary care:

'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)



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)