#lcnuk2025

LUNG CANCER NURSING UK

Annual Conference

🗓️ **19th - 20th June 2025**

📍 **Heathrow**

When treatment becomes end of life

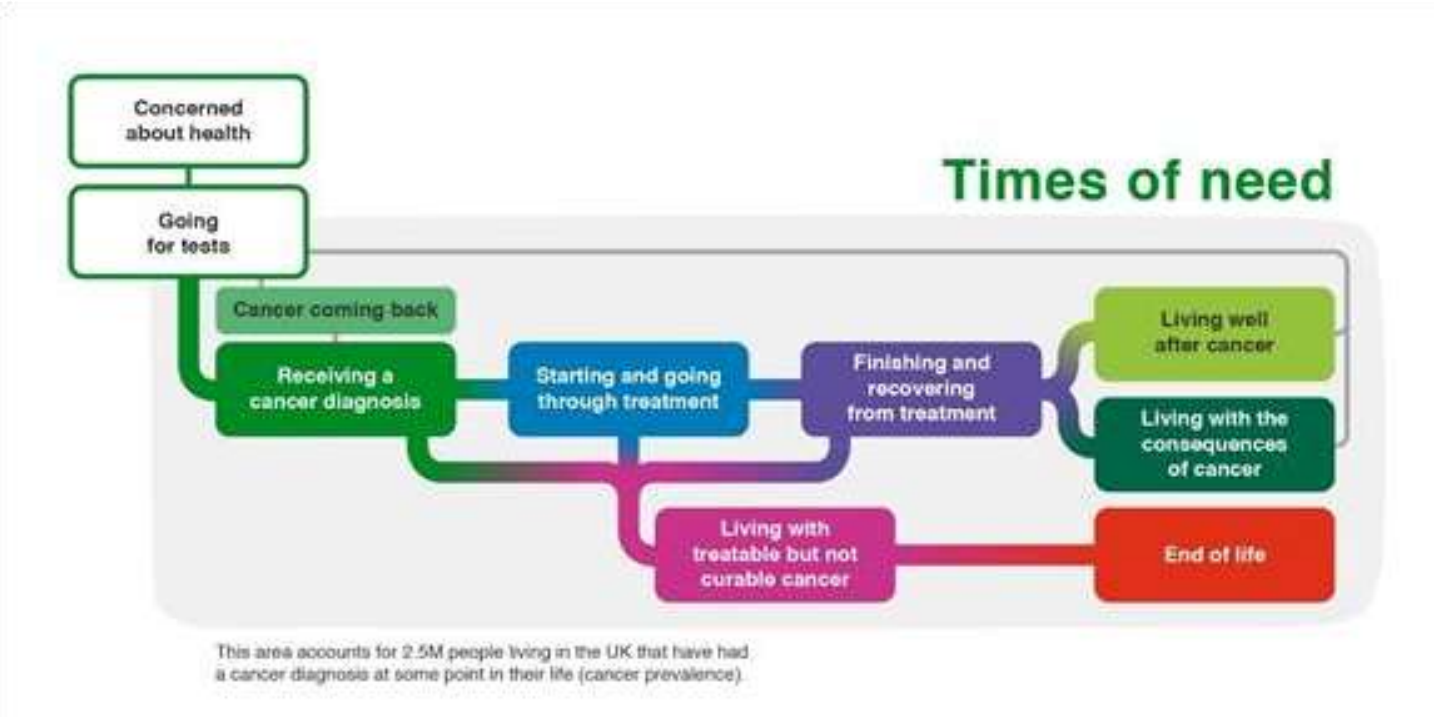
Dr Ollie Minton

Cancer and urgent care

The scale of the challenge

100 patients with cancer as a coded diagnosis are admitted to hospital (unplanned care). How many of them are likely to have died in 12 months?

Acute cancer care is often a time of transition



Acute Cancer Care

Thinking beyond acute oncology

Acute oncology

Oncology based services that are mainly oncologist led, cancer CNS delivered services. They focus on supporting people with a new or established diagnosis of cancer who become acutely unwell and require admission to hospital. Most services in non cancer centres are liaison services, work daytime hours with OOH specialist 24/7 hotline for patients to call.

Acute Cancer Care

The broader term for all the care delivered to people living with cancer who become acutely unwell 24/7. This encompasses primary and community care, generalists in the acute setting, the non cancer MDT as well as the acute oncology and specialist cancer services who will meet someone with cancer during an episode of unplanned care.

Acute cancer care – it's a messy business

- Type 1 - diagnosis of cancer as an emergency

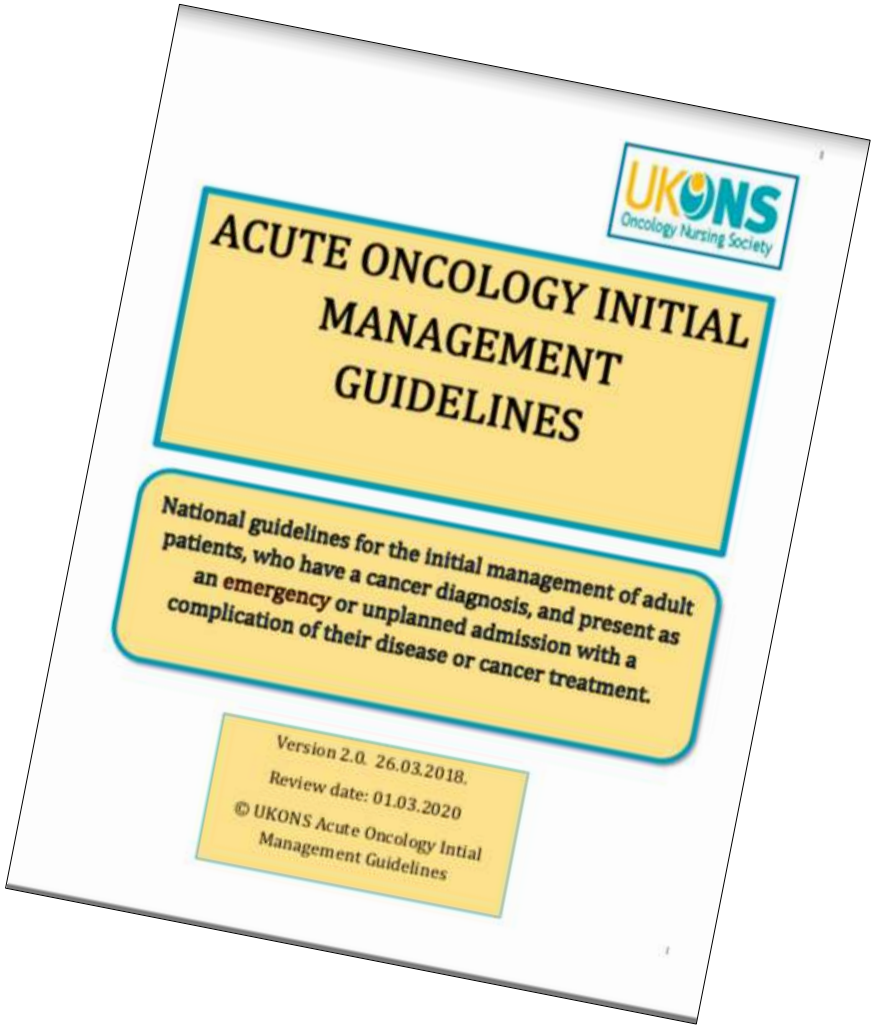
Eg Lung, brain tumours, GI. More likely to have advanced disease and less likely to have anticancer treatment

- Type 2 - complications of anti-cancer treatment

Neutropenic sepsis, complications of novel treatments, chemo issues.

- Type 3 - progression of disease or cancer as a bystander

Nearly 50% of acute cancer admissions, increasing with the age/frailty & co-morbidities of cancer populations



- Reliance on ‘the MDT’ for decision making – is this the right forum for complex decision making?

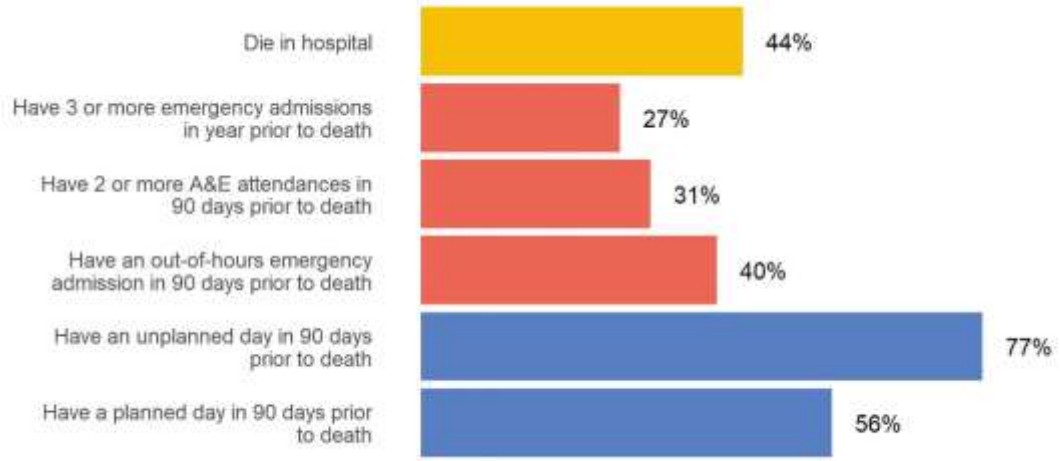
In 624 observed MDT discussions only 14 per cent of discussions included information that did not relate specifically to their tumour, for example the patient’s preference, known comorbidities or psychosocial status.

- Capacity and capabilities – specialist and generalist workforce

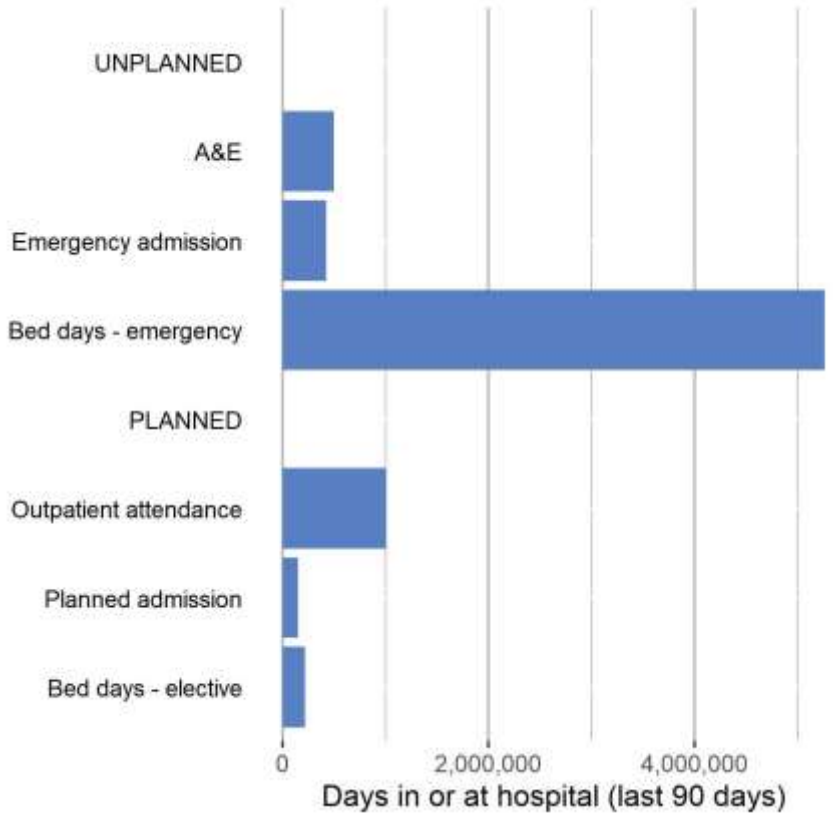
Cancer settings may not be the right place for acute illness in cancer and co-morbidity

AO services are expanding but are they building capacity into acute services?

England wide picture



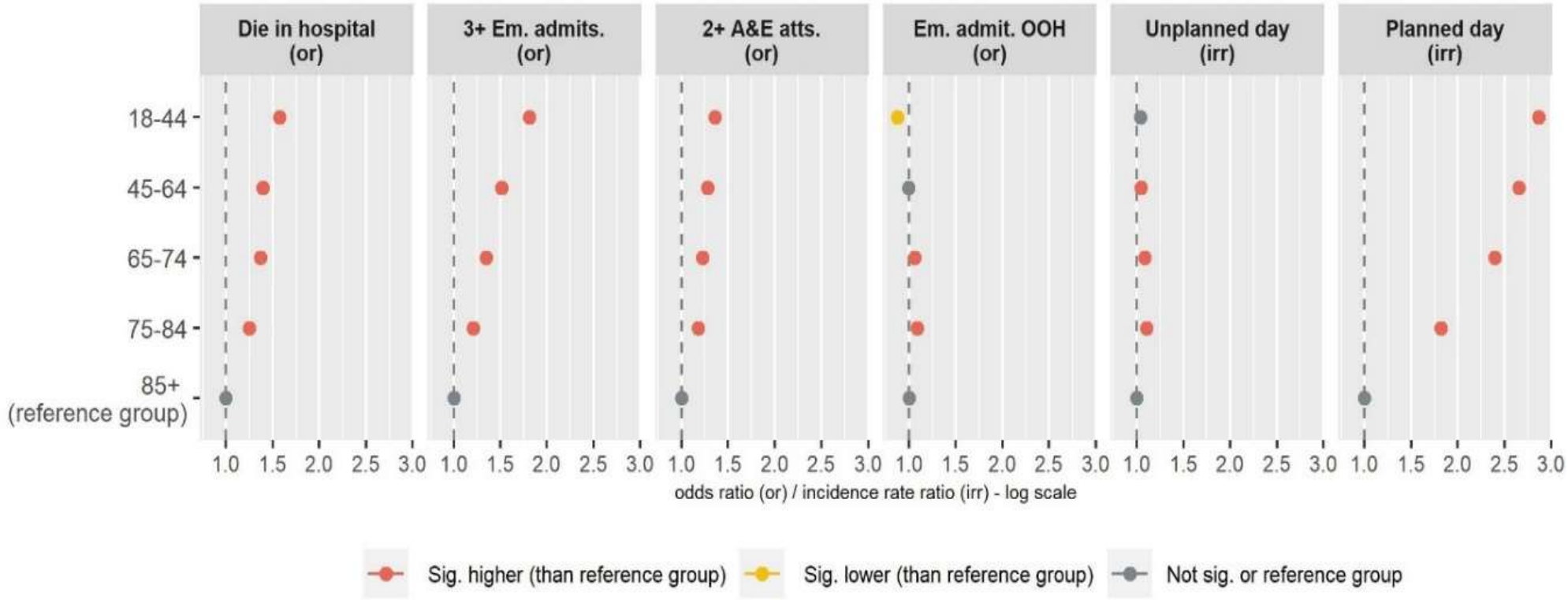
Most of this is unplanned care



Regression analysis

Model variables relating to equity
• Gender
• Rural-urban dweller
• Deprivation
• Ethnicity
• Learning disability, autism, or both
• Living alone
• Dies at weekend
Model variables relating to clinical need
• Age
• Underlying cause of death
Model variables relating to supply of services
• Number of community contacts a person receives in the period before death
• Number of care home beds in a person's local area
• Level of palliative register recording in a person's local area
Model variable relating to geography
• Integrated Care Board

The Picture for cancer patients



MDT working is key as is access to expertise

Key points

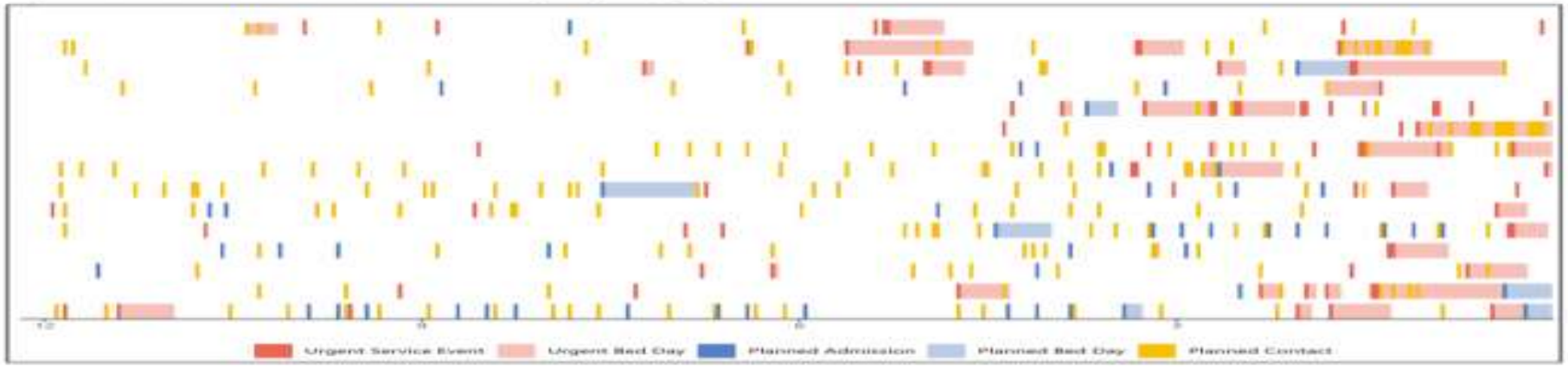
- Cancer patients are high users of urgent and emergency care services
- Presentations may represent symptoms of a new suspected cancer (type I), a complication of cancer treatment (type II) or a complication of a known cancer (type III)
- The majority of cancer presentations requiring an urgent or emergency response are common scenarios to health care professionals and include generally unwell, pain and suspected infection
- Health care professionals need to be aware of the possibility of an uncommon association with recent cancer treatment and should have ready access to local and regional specialist cancer single point of access including cancer treatment and palliative care helplines
- There are a number of readily available published tools and resources to guide cancer patient assessment and initial management
- Cancer patients will benefit from a more integrated offer of community urgent response

Cancer example

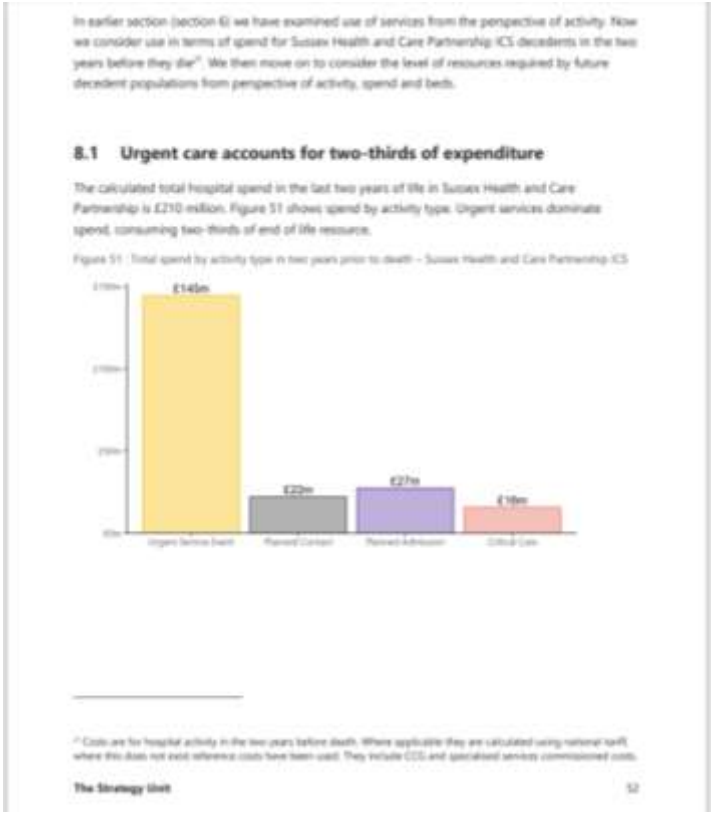
5.4.2 Planned care features highly for those dying of cancer

Analysis of the sample of those dying from cancer (Figure 16) suggests frequent planned contacts and planned admissions. This group is also more likely to have a planned stay in hospital and experience more planned bed days than other cause of death groups. Urgent events and associated urgent bed stays are more likely to occur in the last six months of life.

Figure 16 : Patterns of service use for people dying from cancer



Opportunities



In earlier section (section 6) we have examined use of services from the perspective of activity. Now we consider use in terms of spend for Sussex Health and Care Partnership ICS decedents in the two years before they die[*]. We then move on to consider the level of resources required by future decedent populations from perspective of activity, spend and beds.

8.1 Urgent care accounts for two-thirds of expenditure

The calculated total hospital spend in the last two years of life in Sussex Health and Care Partnership is £210 million. Figure 51 shows spend by activity type. Urgent services dominate spend, consuming two-thirds of end of life resource.

Figure 51 : Total spend by activity type in two years prior to death – Sussex Health and Care Partnership ICS

[*] Costs are for hospital activity in the two years before death. Where applicable they are calculated using national tariff, where this does not exist reference costs have been used. They include CCG and specialised service commissioned costs.

What does excellent EOLC look like?

- Early recognition – last year/years not days
- Earlier access to expertise – both acute oncology & palliative care – seven days a week
- 24/7 support in the community and coordination of care
- Updated education and guidelines to support non expert staff
- Learning from deaths and bereavement support

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If the decision is for end of life care

Known

Patients dying in hospital have variable access to and input from specialist palliative care (SPC) services.

Little is known of the care provided in the absence of such support.

Adds

SPC would intervene in the care of more than half of those dying inpatients not referred for their services.

End-of-life care plans (EOLCP) appear to be a powerful support to non-specialists in providing end-of-life care in hospital.

Policy

Encourage non-specialists in palliative care to consider whether their dying patients may benefit from SPC input.

Researching the most effective structure and function of EOLCP should improve the care received by patients managed by non-specialists.

Local picture (everyone has one)

Date patient was recognised as dying: ___/___/_____

Record observations at least 4 hourly

or affix patient ID sticker here

Month / Year	Date / Time													Date / Time
Pain (reported or observed)	3												3	3
	2												2	2
	1												1	1
	0												0	0
Nausea	3												3	3
	2												2	2
	1												1	1
	0												0	0
Vomiting	3												3	3
	2												2	2
	1												1	1
	0												0	0
Breathless-ness	3												3	3
	2												2	2
	1												1	1
	0												0	0
Respiratory Secretions	3												3	3
	2												2	2
	1												1	1
	0												0	0
Agitation/ Distress	3												3	3
	2												2	2
	1												1	1
	0												0	0
Other, if present (state) _____	3												3	3
	2												2	2
	1												1	1
	0												0	0
Mouthcare - confirm given														
HCA signature														HCA
Registered nurse signature														Reg Nurse
Doctor signature														Doctor

3 = Symptom present, does not resolve with PRN medication	Urgent doctor review of patient and care plan is required for any single symptom score of 3
2 = Symptom present, requires PRN medication to resolve	Care plan continues. If 3 consecutive symptom scores of 2 are present (for any symptom), urgent doctor review of patient and care plan is required
1 = Symptom present	Care plan continues, consider PRN medication
0 = Symptom absent or controlled with CSCI	Care plan continues

Judgement reviews after death

example: end-of-life care

home eolc, **Tep** consulted and made, **symptom** obs , **transfer** to appropriate setting for eolc **ICP** instituted compassion noted, **person centered approach** noted, cons **review** within 24hrs, putative **diagnosis** made, under section, family discussion **nosocomial infection**, pressure damage, **multiple ward moves**, lack of **documentation** between transfers bed moves need for **recognition** of dementia care needs, **absence of holistic care** **Tep** absent, no **frailty** diagnosis, management plan made, **alliative care input** , senior reviews, , **no recognised palliative care need** is, decision for surgery from , decision to operate lack of **gnition of frailty**, management mplications ime to clerking, pmhx noted, **frailty** completed, **Tep** not completed, seen by cons in 24hrs, **severe frailty** identified , wishes not to be investigated , no **anticipatory** prescribing need for 7/7 pall care input , recognised only as **actively dying** , , **consultant review** , lack of notes re anticipatory prescribing , **deterioration**, **met call** , **itu review**, ?tep , lack of tep notation **diagnosis made** , **severity** not **appreciated** , **absence** of **consultant** handover, unclear handovers , **cardiac arrest**, breach in ED missign senior review , absent TEP , absent DNACPR ,

End of life care

- Dying formally recognised
- EOLC prescribing
- DNACPR completed
- TEP adjusted
- CPDP
- Symptom obs
- Family, patient discussions
- Wishes
- Holistic care?

End of life care

Dying cannot be recognised in all patients, but in those for whom it is clinically appropriate, dying should be recognised and documented. If it is clinically appropriate, a programme of end-of-life care may be started at this time. Specialist palliative care teams may be involved in end-of-life care, or advanced care planning. There are clear NICE quality standards for end-of-life care which inform this guidance.

Theme	Very poor	Poor	Adequate	Good	Excellent
Dying recognised and documented	Dying not recognised, with inappropriate intervention and/or escalation leading to potential or real harm to patient, family and staff. This is particularly important if	Dying not recognised when clinically appropriate, with inappropriate intervention or escalation given clinical status. This has the potential to harm patients, family, and staff	Dying recognised and documented as appropriate	Dying is recognised and documented, with appropriate interaction with patient and loved ones	Recognition of dying process is clear and clearly documented, is rational and understood by whole team This recognition is broached with patient/family/loved ones as appropriate ACP/EOLC planning is enacted appropriately and quickly
	family, patient or loved ones have recognised dying, and clinical teams do not enact patient-centred care in these situations.				
EOLC prescribing		Absent or inappropriate prescribing at the end of life Prescribing not in accordance with NICE guidance, without clear reason	Prescribing broadly in accordance with NICE guidance: *care of dying adults in last days of life* or local guidance as appropriate	Prescribing is appropriate and patient-centred, with end-of-life needs recognised and managed appropriately	Evidence of judicious use of medication, including (as appropriate) deprescribing, alteration of medication and use of anticipatory medications Prescribing in accordance with NICE guidance: *care of dying adults in last days of life*
DNACPR and TEP	Evidence that advanced care plans are completed	DNACPR or TEP not completed or considered in a clinical		Attempts made to consider advanced care	(If appropriate) once dying recognised and felt to be irreversible, evidence of completion or consideration

Why aren’t the conversations happening?

Conversations in Acute Cancer Care

Macmillan and UK Acute Oncology Society hosted 4 focus groups in Spring 2024 with healthcare professionals (oncologists and non-oncology HCPs) to understand attitudes towards advance care planning conversations, and why these conversations aren't happening on a more regular basis

Concentrated on the triggers to these conversations and how acute admissions influence practice in this area

Explored attitudes to future planning conversations and response to the prognosis data for AO admissions

“Part of it is that you don’t want to be seen as the bad guy…you’re delivering bad news to them and this can change the relationship.”

Oncologist

Oncologists and non-oncologists have differing views on advance care planning and end-of-life conversations

Oncologists want to focus on more treatment

Most oncologists said that they do have some end-of-life discussions with patients during an acute admission. They spoke more about acute admissions not being the best time for these discussions.

Non-oncologists, however, don't perceive those conversations to be taking place.

Non-Oncologists want to tackle end of life topics more regularly

non-oncologists don't always feel confident in having the conversation as they don't perceive themselves to be the 'experts' in cancer care, especially with many novel cancer treatments.

Oncologists expressed concern that non cancer colleagues can be too pessimistic about prognosis and can fail to interpret cancer specific information

Conversation are taking place 'too late' and patients suffer

Acute settings not seen as the write time or place as family not present, the patient is unwell and not the treating oncologist not present. This leads to further delays as the conversation is deferred to a future time.

healthcare professionals admit that conversations take place 'too late' – and this can mean that patients become distressed at why the conversation wasn't had earlier or are when they forced to have them at the time of acute illness.

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Oncologists' vs other HCP views

'Getting it wrong'

The fear of '*getting it wrong*' is driven both by the nature of the topic itself, but also due to past experiences.

. By avoiding the conversation the risk of '*getting it wrong*' is averted.

Ownership and other colleagues' attitudes & approach

Oncologists were open and honest about the knowledge that some of their colleagues won't/don't have the conversation with acutely unwell patients, either due to a lack of skills, tendency to focus on treatment or because of concerns regarding it not being 'their patient' .

It's becoming an open secret amongst oncology professionals that some professionals 'just don't' have these conversations.

'Fighting the cancer'

Oncologists tend to propagate the narrative that healthcare professionals are meant to be consistently seen to be 'fighting cancer' on behalf of patients. This is something that non-oncologists highlight rarely happens in other medical specialties.

This close relationship between patient and oncologist reinforces the issues around patient ownership but is valuable to people living with cancer.

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Oncologists want to focus on the immediate issue and potential new lines of treatment

But non-oncologists are concerned about the ownership 'claimed' by oncologists and navigating around this

‘What Matters to me’ – a call to action for HCPs working in cancer care

Ownership

There needs to be an open and frank conversation about ‘ownership’ of advance care planning between patients, oncologists, non-oncology professionals.

Wider triggers to have a ‘what matters to me’ conversation

There needs to be a wider range of triggers for these conversations in cancer care. These must be recognised and communicated clearly between oncologists, patients and non-oncology professionals – giving them the ‘go ahead’ to initiate conversations

Accountability

There needs to be greater accountability and feedback within oncology practices for when these conversations *aren't* happening appropriately

Confidence/aptitude

There need to be better access and funding for advanced communication skills for those who meet acutely unwell patients with cancer

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Potential solutions

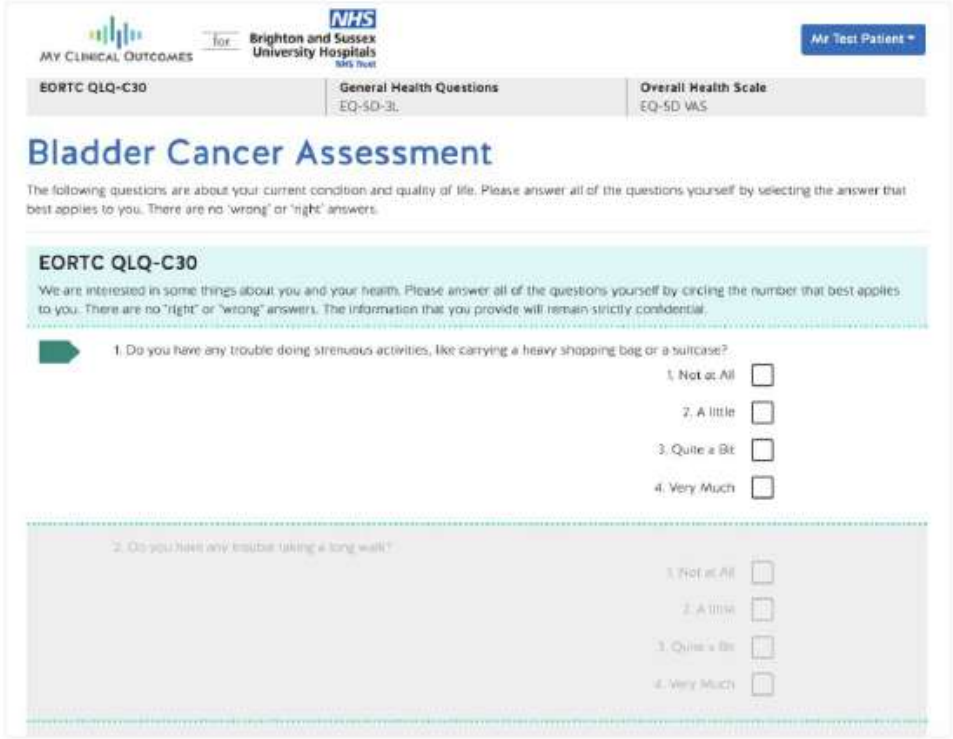
- Routine use of PROMs is recognised as a priority in the **NHS Cancer Strategy** for ‘living with and beyond cancer’
- Clinicians often under-report patient symptoms and may miss up to 50%
- Routine integration of PROMs into clinical practice has been shown to **improve survival** for patients
  - early recognition and targeted intervention
  - adjustments to treatment allowing patients to tolerate systemic anti-cancer therapy for longer

PROMS

Brighton and Sussex University Hospitals NHS Trust

MCO for BSUH

Assessment



MY CLINICAL OUTCOME

Assessments:

- EORTC QLQ-C30 (Questionnaire developed to assess the quality of life of cancer patients)
- EQ-5D-3L (General Health Questions)
- EQ-5D VAS (Overall Health Scale)

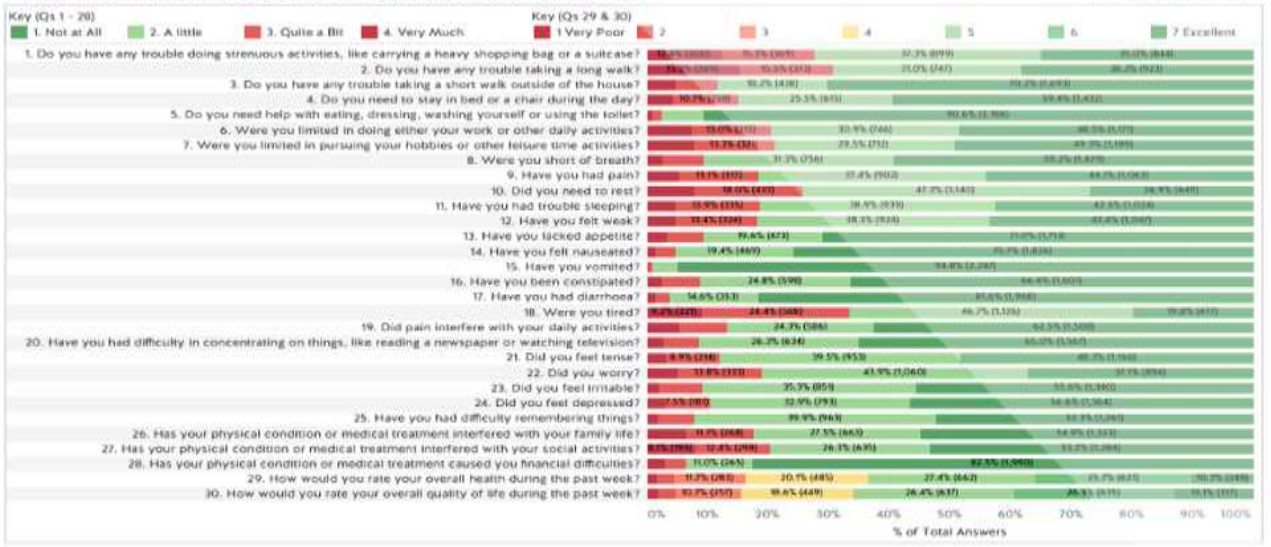
Patients receive an email reminder to complete scheduled assessments at 2-week intervals, regardless of their cancer type

Symptom burden

EORTC QLQ-C30 - Response Detail

All Validated Patients, All Assessments: 22 September 2020 - 31 May 2021

MY CLINICAL OUTCOMES



Total Assessments By Cancer Type

Breast (Primary)	Bladder	Bowel	Breast (Secondary)	Kidney	Liver	Lung	Oesophageal	Other	Ovarian	Pancreatic	Prostate	Stomach	Total
19	26	27	763	44	40	37	41	728	62	46	539	40	2,412

Source: Extract from MCO Data Visualisation Package. Means calculated across all completed assessments. Analytics data only for patients validated by a BSUH hospital staff member.

Context

Evidence supports that providing good, early supportive care can improve quality of life measures for patients with terminal conditions, possibly lengthening their survival and reducing the need for aggressive treatments towards end of life.

University Hospitals Sussex NHS Foundation Trust (UHS) implemented an Enhanced Supportive Care (ESC) intervention in September 2020, as part of an NHS England programme. The intervention seeks to identify patients with cancer who may benefit from earlier access to supportive care. A team was deployed on the acute wards to identify such patients and provide ESC.

Monetised benefits included:

- Reduction in non-elective admission rate
- Reduction in non-elective average length of stay

Other benefits included:

- Proactive patient management with remote PROMS
- Earlier provision of supportive care for patients at end-of-life

Return on investment locally

Health economic results

A real-world, mixed methods approach was adopted. A cost-benefit analysis explored the possible future impact of the ESC programme in terms of real monetary cost, with a 5-year forecasted net present value (NPV) and benefit-cost ratio (BCR). Two benefit streams were modelled across all three scenarios: non-elective (NEL) admission rate and NEL average length of stay (LOS).

Scenario 1: patient discharge code 79 (sub cohort)

1.43	0.95	£121k	1.2
average reduction in NEL length of stay (days)	reduction in average number of NEL admissions per patient	5-year net present value estimate (2020/21 – 2025/26)	5-year benefit-cost ratio estimate (2020/21 – 2025/26)

Scaled up to regionally and beyond

Conclusions

- Changes in Quality life scores sensitive indicator – toxicity / progression etc
- Attending as an emergency – regardless of reason - clear indicator of deterioration vs elective care – should mandate supportive / palliative care discussions
- Collaboration key for an in reach service – acute medicine want guidance for all oncological problems and don’t discriminate

Ambition:

Every person with cancer who has an unplanned acute admission has an opportunity for a personalised care planning conversation and care plan to meet their needs

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When a person living with cancer is admitted into hospital through emergency and unscheduled care, this often marks a turning point in their illness. Healthcare professionals working in acute cancer care should:

See it – recognise an acute admission as a point of transition for a person living with cancer.

Say it – take the opportunity to talk to the person and their family about what matters to them, including risk of acute illness, future admissions & death

Share it – ensure this conversation is the basis of an advance care plan to be shared more widely.

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