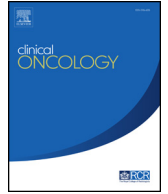




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Original Article

A Short Report Examining the Introduction of Routine Use of Patient-Reported Outcome Measures in a Mixed Oncology Population

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Abstract

Aims: People living with treatable but not curable cancer often experience a range of symptoms related to their cancer and its treatment. During the COVID-19 pandemic, face-to-face consultations were reduced and so remote monitoring of these needs was necessary. University Hospitals Sussex implemented the routine use of electronic remote patient-reported outcome measures (PROMs) in a mixed oncology population, focusing on those with treatable but not curable cancers.

Materials and methods: Over a 9-month period, patients were invited to register with *My Clinical Outcomes* (MCO) – a secure online platform for the collection of electronic PROMs. They were prompted by e-mail to complete assessments (EORTC QLQ-C30, EQ-5D-3L and EQ-5D VAS) routinely every 2 weeks. The team monitored patient scores and changes in these prompted clinical interventions.

Results: In total, 324 patients completed at least one assessment. The median number of assessments completed by each patient was eight. The most represented tumour groups were secondary breast (28%), prostate (25%) and other (32%). Median scores for the assessments did not deteriorate in a clinically or numerically significant way for patients living with non-curable conditions for the majority of patients monitored.

Conclusion: Routine collection of electronic remote PROMs is an effective and useful strategy to provide real-time clinical feedback to teams. With integration into existing systems, online platforms (such as MCO) could provide efficient and patient-centred information for those providing care for people with cancer. © 2021 The Royal College of Radiologists. Published by Elsevier Ltd. All rights reserved.

Key words: Palliative care; PROMs; remote monitoring; supportive care

Introduction

In England, it is estimated that over 110 000 people are living with cancer that is classified as ‘treatable but not curable’ [1]. These patients often experience symptoms associated with their cancer and the therapies they receive in its management, impairing their quality of life and impacting on their ability to complete planned treatment courses. Specialists in supportive and palliative care have skills in symptom management that can be used to improve the experiences of this patient group, but identifying those in need prior to unplanned hospital admission or symptom

crisis is challenging. Patient-reported outcome measures (PROMs) can help to identify unmet needs. These are outcomes directly reported by the patient – describing their own subjective experience – and have been widely used in both routine cancer treatment and clinical trials for over 20 years [2,3].

In the Sussex Health and Care Partnership Integrated Care System, 84% of people attend the Emergency Department in the 2 years prior to death and 81% have at least one emergency hospital admission. People with cancer access all health services (with the exception of critical care) more than those dying of other causes [4].

Clinicians often under-report patient symptoms and may miss up to 50% [2]. This can lead to poor symptom control and impact on quality of life. Meanwhile, the integration of PROMs into routine clinical care has been shown to increase

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survival for patients – through a combination of early recognition and targeted intervention or adjustments to treatment allowing patients to tolerate systemic anti-cancer therapy for longer [5].

It is estimated that the cancer specialist nurse workforce needs to increase by 84% in order to deliver personalised care to all people living with cancer [6]. Remote collection of PROMs aids in triaging and prioritising patients for clinical review, and results in focused consultations and increased patient satisfaction [7]. The routine use of PROMs is recognised as a priority in the NHS Cancer Strategy for ‘living with and beyond cancer’ [8]. Reviewing PROMs prior to clinic appointments can help tailor interactions and aid clinicians in holistic care – for example, enquiring about psychological wellbeing, which is often overlooked in a busy clinic appointment [9]. Recording PROMs focuses patients on their own symptom burden and can provide a visual representation of this trend over time. PROMs have been shown to improve communication between patients and healthcare professionals [10,11] and increases information available to clinicians to aid in shared decision making – a National Institute for Health and Care Excellence (NICE) priority with recently updated guidelines [12].

Feasibility studies have shown that electronic PROMs are acceptable to most patients locally at the Sussex Cancer Centre, including those who are less digitally engaged [13]. The use of technology to remotely monitor patients is particularly pertinent in the present context of the COVID-19 pandemic. Reductions in face-to-face consultations and the on-going uncertainty about further waves of infection and their potential impact on the delivery of cancer services supports the case for remote PROM systems to be incorporated into routine practice.

Materials and Methods

Study Setting

The Sussex Cancer Centre at the Royal Sussex County Hospital offers tertiary cancer services to a population of about 1.2 million patients living in Brighton and the surrounding areas (from Chichester to Rye and Brighton to East Grinstead). The enhanced supportive care (ESC) service at Royal Sussex County Hospital aims to provide early access to supportive and palliative care for patients living with treatable but not curable cancers. As part of this, the team utilises *My Clinical Outcomes* (MCO) – a platform for the collection of electronic PROMs.

Ethics/Governance and Funding

This project was designed and funded as a service evaluation via the Enhanced Supportive Care Project commissioned by NHS England/Improvement with support from the Sussex Cancer Fund. All data extracted was anonymised and maintained in a secure database. The project was

processed using NHS HRA REC decision tool and was found not to require NHS REC review.

Patient Population

Eligible patients were adults living with treatable but not curable cancer under the care of the Sussex Cancer Centre, over a 9-month period (22 September 2020 to 7 June 2021). There were no restrictions to primary cancer diagnosis, comorbidity or other demographic details. It was introduced as a part of routine care. We would estimate that about 20% of eligible patients registered.

Study Assessments

Patients were invited to register with MCO, inputting their tumour type and treating consultant. They were prompted by e-mail to complete three questionnaires routinely every 2 weeks, but could do so more frequently if desired. These included:

- EORTC QLQ-C30 – a 30-question assessment of health-related quality of life for people living with cancer, focusing on common physical, financial, social, cognitive and emotional impacts of disease [14]. Originally developed to assess quality of life for patients undergoing clinical trials, it has been extensively tested in cross-cultural settings and subsequently refined.
- EQ-5D-3L – a five-question assessment of mobility, self-care, ability to continue usual activities, pain/discomfort and anxiety/depression [15].
- EQ-5D VAS – an assessment using a visual analogue scale from 100 (best imaginable health) to 0 (worst imaginable health) [15].

Assessments

The ESC team reviewed patients’ assessments. The research team agreed that a score drop of 15 points in EORTC QLQ-C30 or a newly reported score of ‘3 (quite a bit)’ or ‘4 (very much)’ for pain, nausea, vomiting, constipation, shortness of breath or depression would act as a trigger for intervention. Initially this involved contacting patients directly. This was later refined to contacting their tumour-specific teams to prompt targeted interventions, as they were best placed to coordinate care, particularly as tumour-specific teams may already be engaged in supporting patients with that symptom.

Data were analysed by tumour group, describing median (and interquartile range) assessment scores between first and last assessments.

Results

In total, 326 individual patients registered during the study period; 324 patients completed at least one assessment over six different hospital sites. Of these, 51%

identified as male and 49% identified as female. The median patient age was 69 years (interquartile range 59–75 years). The median number of assessments completed by each patient was eight (interquartile range 4–12; range 1–17) across a range of tumour groups. The most represented tumour groups were secondary breast (28%), prostate (25%) and other (32%) (Table 1). Table 2 shows the change in these scores over time by tumour type. Figure 1 illustrates trajectories for score variations in patients with different clinical courses (1, rapid progression of disease; 2, positive response to treatment; 3, poorly tolerated treatment with disease progression; 4, positive initial response to treatment followed by development of toxicity and disease progression).

Overall, the symptom that caused the most significant burden to patients was fatigue, necessitating rest and limiting their daily activities. This was scored as ‘quite a bit’ or ‘very much’ for over 25% of the sample. However, overall quality of life was preserved in 75%, rating it as good or above.

Discussion

This study shows that real-world remote electronic PROMs collection is feasible and adds value to cancer care. Patients are willing to consistently engage with electronic PROMs over a period of months.

The minimal reduction in median assessment scores suggests an ongoing response to treatment and minimal treatment-related toxicity. This is reassuring at a time of reduced face-to-face monitoring as necessitated by the COVID-19 pandemic.

Breast cancer and prostate cancer are the most common cancer types in the UK [16], which is reflected in our study population. Lung cancer and bowel cancer are the third and fourth most prevalent in the UK, although represented only 2% and 1%, respectively, of patients in our dataset. Barriers to engagement in this group of patients and clinicians are an area of focus for further development.

Fatigue is a common symptom impacting on quality of life for patients with advanced cancer, both due to the disease and the side-effects of treatment [17,18]. There are ongoing clinical trials investigating the effectiveness of methylphenidate versus placebo for managing this [19] and an additional aim of the ESC team is to increase patient access to clinical trials.

Strengths and Weaknesses

The real-world, prospective nature of this study gives it face validity. The broad range of tumour types represented shows that remote collection of electronic PROMs is acceptable to patients living with cancer and clinically useful to a variety of cancer professionals. There were, however, some limitations in how the system was configured for the project. For example, the options for ‘diagnosis’ were limited, resulting in a large proportion of patients

registering under the ‘other’ category, which covers a wide range of tumour groups, including melanoma, head and neck and haematological malignancies, complicating analysis by tumour type. For simplicity, the MCO platform was not integrated with other IT systems involved in the care of cancer patients at our centre for this project, but this may have been a barrier to engagement for some clinical teams.

Although the use of PROMs is invaluable in capturing patient feedback and experience, some reported symptoms may be related to other underlying comorbidities rather than directly related to the cancer. There is evidence of the benefit of self-monitoring for a range of chronic conditions, including chronic obstructive pulmonary disease and heart failure, resulting in reduced hospitalisation and readmission [20]. Therefore, the routine collection of electronic PROMs may have some unintended benefit in the management of non-cancer comorbidities.

PROMs can be used to efficiently triage patients for review by stretched clinical teams, resulting in targeted interventions for those most in need. In a recent paper about their own version of electronic PROMs, the Christie reported initial limited engagement from clinical teams as the electronic PROMs was a separate online system not integrated into their main computer system used by clinicians. Engagement has improved following integration of the systems [9]. We hope that similar integration will help to increase engagement from site-specific teams in our own area.

Implications of Findings and Areas for Further Exploration

There is scope for developing the web-based program to include algorithms or links to resources for patients who flag increasing symptoms in a particular area. This approach has been shown to be effective in other studies [18]. We would hope this could be done by support workers with a decision tree algorithm or guidance, such as the UK Oncology Nursing Society [21], to allow for earlier identification of problems. This would be in addition to clear guidance around toxicity management already in routine practice.

Table 1
Number of patients registered by tumour group

Diagnosis	Number of patients (% of total)
Bladder	3 (1)
Bowel	3 (1)
Breast (primary)	5 (1)
Breast (secondary)	92 (28)
Kidney	7 (2)
Liver	3 (1)
Lung	6 (2)
Oesophageal	5 (1)
Ovarian	7 (2)
Pancreatic	8 (3)
Prostate	79 (25)
Stomach	5 (1)
Other	103 (32)

Table 2
Change in median (and interquartile range) assessment scores between first and last assessments by tumour group

Diagnosis	First assessment			Final assessment*				
	n	EORTC overall	EQ-5D overall	EQ-5D VAS	n	EORTC overall	EQ-5D overall	EQ-5D VAS
Bladder	3	56.90 (55.10, 84.50)	0.36 (0.10, 0.80)	59 (50, 90)	3	95.60 (33.10, 100.00)	1.00 (0.09, 1.00)	97 (30, 97)
Bowel	3	58.70 (52.10, 87.10)	0.69 (0.69, 0.85)	70 (20, 75)	3	51.10 (31.30, 81.60)	-0.02 (-0.07, 0.90)	50 (30, 65)
Breast (primary)	5	88.60 (86.40, 90.10)	0.80 (0.73, 0.82)	85 (80, 98)	3	94.80 (74.10, 95.40)	0.82 (0.80, 0.85)	87 (80, 95)
Breast (secondary)	92	78.50 (66.40, 87.50)	0.76 (0.62, 0.85)	70 (50, 81)	88	77.70 (63.70, 87.00)	0.69 (0.62, 0.81)	64 (49, 80)
Kidney	6	86.90 (78.50, 93.80)	0.94 (0.85, 1.00)	77 (50, 91)	5	91.40 (74.40, 99.10)	1.00 (0.76, 1.00)	70 (50, 91)
Liver	3	91.60 (86.10, 97.40)	1.00 (1.00, 1.00)	70 (50, 100)	3	88.90 (83.20, 94.70)	1.00 (0.73, 1.00)	55 (39, 100)
Lung	6	68.10 (39.90, 72.60)	0.47 (0.19, 1.00)	55 (30, 85)	6	60.20 (42.90, 86.00)	0.69 (0.08, 0.81)	38 (25, 60)
Oesophageal	5	86.00 (77.10, 90.20)	0.73 (0.69, 0.85)	80 (66, 88)	5	89.10 (65.70, 89.90)	0.81 (0.73, 1.00)	70 (62, 80)
Ovarian	7	89.20 (83.90, 95.20)	0.88 (0.80, 1.00)	86 (50, 92)	6	75.50 (47.40, 92.50)	0.65 (0.31, 0.76)	54 (17, 70)
Pancreatic	8	77.20 (62.40, 80.10)	0.73 (0.60, 0.80)	70 (55, 77)	7	67.20 (35.30, 79.50)	0.66 (-0.07, 0.81)	60 (12, 63)
Prostate	79	87.60 (79.00, 94.70)	0.88 (0.73, 1.00)	80 (60, 90)	74	88.50 (74.90, 94.20)	0.85 (0.69, 1.00)	80 (52, 91)
Stomach	5	78.70 (27.60, 81.20)	0.73 (0.69, 1.00)	60 (51, 61)	5	69.40 (68.60, 89.10)	0.73 (0.62, 0.88)	60 (44, 60)
Other	102	85.80 (71.80, 92.70)	0.80 (0.69, 1.00)	75 (65, 87)	91	85.20 (74.70, 92.20)	0.80 (0.62, 1.00)	75 (60, 88)

* Excluding those who completed only one assessment.

The questionnaires used are well-validated tools applicable across cancer and treatment types but the fact that median scores did not deteriorate significantly for the majority of patients may indicate that these instruments are not sensitive to all potential symptoms. It is important not to overburden patients with extensive questionnaires as this will negatively impact on engagement. However, tailoring of questionnaires to use modules or questions

specific to diagnosis or treatment type may improve the detection of symptoms.

Feasibility studies have shown that electronic PROMs are an option for older and traditionally less computer literate cohorts, but that they may benefit from completing questionnaires in a clinic setting with support available [13]. We did not explore the reasons behind non-registration in our population, but that is an area for further investigation.



Fig 1. Examples of changes over time in EORTC QLQ-30 scores.

Unfortunately, there was not an alternative option to collect PROMs for people without internet access or who did not speak English, but anecdotally we are aware that for some of these people friends and family members were able to facilitate collection.

It would be beneficial to gather patient feedback on the use of PROMs and their experiences of whether it has shaped care or any other barriers to use. Although there is evidence to suggest that early palliative care intervention improves quality of life outcomes and even survival for patients [22], more exploration is needed around the effect of routine use of PROMs on admissions avoidance and unplanned contact with healthcare, particularly in the changing healthcare landscape with COVID-19.

Conclusion

Electronic PROMs are useful for the remote monitoring of patients living with cancer and identifying those who need urgent intervention. We saw a smaller reduction in quality of life scores than expected, suggesting that this population are inherently stable over a 9-month period with some exceptions where scores deteriorate. Remote monitoring may therefore have a role to play in detecting those patients who do deteriorate while reducing the need for frequent clinical assessment of the majority. Integration of electronic PROMs into IT systems and routine care structures with clear and defined clinical responsibilities is needed to efficiently use the available workforce. Further work is ongoing, embedding PROMs as part of routine care for all tumour groups and site-specific teams.

Conflicts of interest

T. Williams reports a relationship with *My Clinical Outcomes* that includes: employment and equity or stocks.

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Enhanced Supportive Care Evaluation overview

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

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

average reduction in NEL length of stay (days)

0.95

reduction in average number of NEL admissions per patient

£121k

5-year net present value estimate (2020/21 – 2025/26)

1.2

5-year benefit-cost ratio estimate (2020/21 – 2025/26)

Context and additional scenarios

Scenario 1 focused on a sub-cohort of patients who died in hospital (20% of patients seen by ESC team). Scenario 2 forecasts results from all patients seen between September 2020 - September 2021 for UHS, and Scenario 3 forecasts the potential impact of spread across the South East.

External influences, such as COVID-19, may be partially attributed to changes in benefit streams seen.

The BCR indicates the NHS non-cash releasing benefits for every £1 spent. These benefits do not include the potential wider social benefits of the intervention, such as improved patient care and quality of life.

Total NPVs for the cost-benefit analysis over the financial 5-year period (2020/21 – 2025/26) for Scenarios 2 and 3 are shown below.



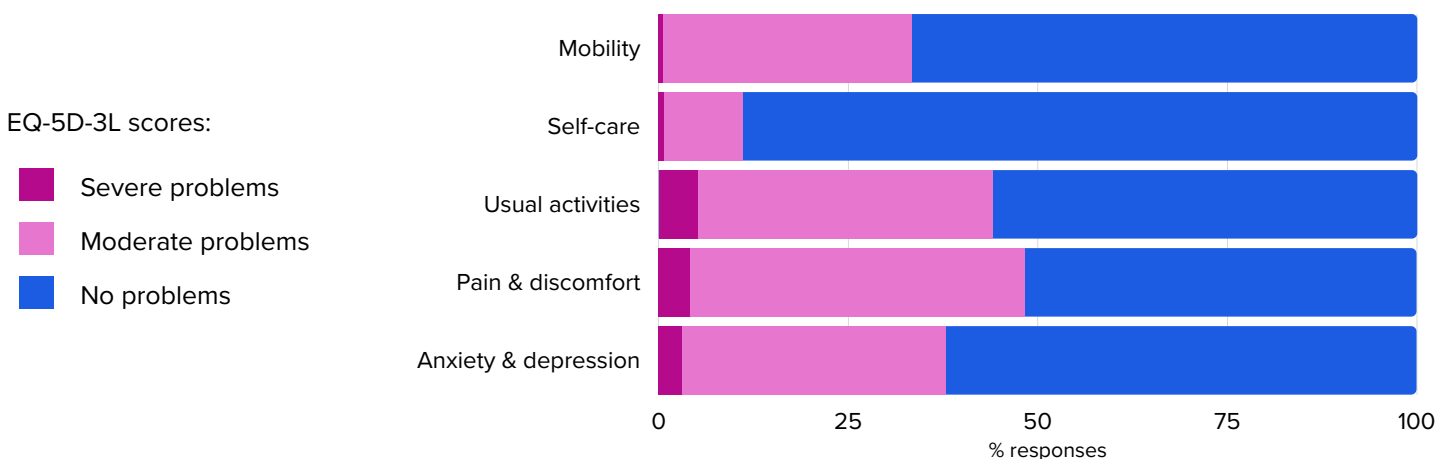
Quality of life

The My Clinical Outcomes solution enabled regular remote recording of patient reported outcome measures (PROMs) to support ongoing patient monitoring and symptom management.

The chart shows all recorded EQ-5D-3L scores from the patients seen by the ESC team across the intervention period.

Patients reported the highest proportion of 'severe' to 'moderate' problems for the 'pain & discomfort' and 'usual activities' domains.

A lack of baseline data limited the analysis and comparisons that could be drawn, particularly as a decline in quality of life can often be seen for end-of-life patients.



Staff and patient feedback

Acute medical consultant

"Your team makes an enormous difference not only to the patients you see, but also to those you don't – through education, through visibility, and simply through familiarity with how you work – meaning that clinicians think more readily of palliative care inputs than they would if you didn't exist."



"if [ESC nurse] had not stepped in and been the professional, knowledgeable and compassionate team member he clearly is, I really do not want to think what could have happened. [ESC nurse] was able to identify that my Dad was presenting serious symptoms which needed further investigation and was able to support with pain management and be the conduit between my Dad and the acute medical team."



Family member

Key recommendations

Service expansion

The service is not limited to patients with palliative cancer or within the Sussex region - other patients with chronic conditions would likely benefit from ESC. Further exploration would be recommended to identify whether the benefits modelled vary for patients with other chronic conditions.

Clinical buy-in

Surveys indicate that clinical buy-in from other teams on the wards is crucial in successful implementation. Further engagement would help disseminate the benefits of providing ESC. This could facilitate service provision, benefitting patients and the healthcare system.

Staff training

Survey results indicated that further staff training or support may be beneficial. Such training may improve staff confidence in identifying patients and delivering ESC. This could improve patient outcomes, as well as improve staff satisfaction and retention.

Conclusion

ESC provides earlier access to supportive care for patients who are towards end-of-life or with treatable but not curable cancer. It is typical to see substantial use of the healthcare system within these cohorts; therefore, the primary benefits identified for this programme focus on a reduction in the use of hospital resources to generate healthcare cost savings.

The intervention data showed a reduction in the NEL admission rate and NEL LOS for the patient cohort for Scenario 1 within the health economic modelling, seen as cost savings to the system.

The cohort of patients identified within the programme are likely to have late-stage or non-curable cancer, or require end-of-life care. This stage of a patient's pathway can be a distressing time.

Through earlier access to supportive care, the intervention aims to improve quality of life for patients. Though this has not been explored within the health economic model in this evaluation, the ESC programme is thought to contribute to positive social benefits for patients, their families, and their friends.

Brighton & Sussex University Hospital Enhanced Supportive Care Case Study



Ms Bright is a 69-year-old lady with a background of metastatic melanoma. She started having seizures at home and was brought into the Emergency Department (ED) one morning by a paramedic team. On arrival she was postictal and therefore not able to fully engage in a complete assessment.

The ESC Team are based on the acute floor to allow for early recognition of patients who would benefit from the service and support teams to make early referrals.



1. Early involvement of supportive and palliative care services. How Ms Bright accessed ESC

On arrival Ms Bright was seen by the Emergency Department consultant who requested a CT head scan. The ESC team were able to identify and see her swiftly, without requiring specific additional referral process to be completed.

ESC CNS Katie discussed the patient with the consultant and completed her assessment. She identified that Ms Bright had a history of metastatic melanoma therefore was already known to acute oncology and palliative care teams.

This situation was a good opportunity for the ESC team to work proactively with the patient, family and clinical teams to help move her through the system as swiftly as possible and potentially avoid an admission and prolonged stay in acute care. Katie escalated the CT Head request and report, to enable early discussions and decision making from relevant clinical teams.

On return from the CT scan, Ms Bright was referred to the acute medical team. The ESC team spoke with the ED consultant, the medical team and with the acute oncology team to coordinate a plan.

Katie's role as a link between teams ensured collaborative working for all whilst supporting Ms Bright and her family around decision making and discharge planning. In this instance Ms Bright had had a seizure and was already known to the teams

Table 1: A summary of medical tests Ms Bright may have undergone and teams that would be involved in her treatment had she been admitted.

Tests/procedures	Teams involved
CT scan - head	Oncology
Chest X-Ray	Palliative care
Blood test & screens	Dietetics
MRI scan - head	Physiotherapy
	SALT
	Pathology
	Nursing - 3 different settings
	Pharmacy
	Occupational Therapy
	Medical (ward)
	A+E
	Social Services
	Paramedics
	Porter service
	Phlebotomy
	Radiology
Total: 4	Total: 16

because of her ongoing cancer diagnoses; she had multiple metastases and her clinical prognosis was poor. Without the intervention of the ESC team within ED, the normal processes would have focussed more on the treatment of her seizures.

CNS Katie “Having us involved early on in those decisions lets us plan for these patients so that it stops patients going through the system. Admissions are being avoided following conversations with their oncology teams or with early palliative care input then we’re able to turn these patients around and have them discharged safely with a follow up plan.”

Unfortunately, this process would have inevitably included a series of other tests, investigations and procedures which in turn would include moving around the site, disruption to rest and sleep; generating anxiety and distress and in some instances additional discomfort. It is likely that Ms Bright would have interacted with approx. 16 different teams and departments in the first few days alone.

Whilst these may all be relevant within a medical pathway, they add to the plethora of strands of communication, information sharing not just within hospital teams but for concerned family members trying to understand the significance of each step on Ms Bright. It is often part of the process that is very time consuming for hospital staff, long periods waiting on the line for family members, subtle differences in conveying messages and interpretation occur; where muddles about plans occur, that can lead to complaints further down the line.

CNS Katie: “We are now based on the acute floor and feel like part of the team. We are able to discuss patients and take referrals earlier, proactively picking up patients and making plans for them and discussing with other teams.

Acute oncology is really stretched across the hospital as they do not have a dedicated ward at present, we are able to review Acute Oncology Service patients and then liaise with their consultant and clinical nurse specialist. It makes for a quick, seamless assessment and avoids duplication. “

Prior to her admission Ms Bright was living with her 92-year-old mother. She had recently moved in to support her mother as she was becoming more dependant. Following a consultation with her oncology consultant, some of her cancer treatment had been stopped due to side effects which she felt were impacting on her quality of life. Her family had noted a decline in her mobility and independence that was followed by a seizure. The situation and sudden deterioration were very distressing for her family.

CNS Katie: “Completing holistic assessments enables us to discuss any needs or concerns patients have about any area of their life. It is not only about the physical symptoms or the side effects of treatment. Having these conversations early on in the patients’ journey will allow for future planning which will be tailored to the individual.”

The ESC team were clear that, given the prognosis and immediate preadmission situation it was unlikely that Ms Bright would be able to return home and resume independence again. Even if all the usual processes for her along the pathway were completed smoothly, Ms Bright would still spend a period of time in hospital, which might be something that would end up consuming a significant proportion of her remaining life without adding to the quality of that time and keep her away from her family.

An acute admission would have had an impact on Ms Bright and her family, especially her elderly mother who may not have been able to visit due to Covid-19 visiting restrictions and the practicalities of getting to and from the hospital. There may have been financial, economic, social, emotional and practical impacts on Ms Bright’s family from the unanticipated emergency and stretching across each day of her hospital stay. Car park charges alone would cost £10 per day¹.

From a clinical perspective there was also the possibility that, once admitted, Ms Bright was at higher risk of picking up hospital acquired infection or being exposed to Covid-19, which would cause distress and increase her risk of death in hospital.

CNS Katie "With our referrals and working closely with palliative care, we've built up our relationship with the community palliative care team and our local hospices as well, which we liaise with and as we're making earlier referrals for palliative care patients. We've been able to refer and discharge to Hospices from the acute floor, which is not something that normally happens, so that's been a real positive. Making those connections and communicating with those teams have allowed us to improve patient experience and ease the pressure on the acute floor."

After Katie's assessment it was felt that the most appropriate plan would be for rapid discharge to hospice care rather than progressing the admission further along the acute pathway and admit Ms Bright to an acute ward bed. This would minimise the risk of hospital acquired infection and reduce the number of people with whom Ms Bright would have to come in contact with – medical, nursing, AHP, oncology and palliative care teams – and minimise the number of additional referrals, assessments, and interventions – the departments involved in her care.

Ms Bright and her family agreed with Katie's plan, however unfortunately a hospice bed was not available until the following day. So, Ms Bright was moved to the Acute Medical Unit to await the bed. During this time the ESC team continued to act as the coordinator and liaison between the teams and the family.

The next day Ms Bright was successfully transferred to the hospice where she lived for 10 days until her death, during which time she was able to spend time with her family in a calmer setting than a busy acute hospital ward.

What would have happened if ESC hadn't been available?

It is likely that Ms Bright would have been admitted onto the Acute Medical Unit under the care of a medical team, and eventually moved to a medical inpatient ward. This process would probably have involved several additional procedures, investigations and reviews by advisory teams.

Table 2: A summary of the tests and interventions Ms Bright had and those associated with a similar acute admission

Tests and interventions Ms Bright had during her admission	Further tests and interventions Ms Bright may have had without ESC intervention
Discussion with Acute Oncology	MRI brain scan
Discussion with Palliative care team	Neurologist specialist intervention
CT Head Scan	IV fluids
Chest X-Ray	Arterial Blood Gases if further seizures
Blood tests	Medical Emergency Team calls
	Antibiotics
	Further blood tests
	Catheterisation
	NG tube insertion (possibly with videofluoroscopy) and an NG feeding regime
	New medicines and possible side effects

Ms Bright would have been treated by several inpatient ward teams daily, including nursing, medical, pharmacy, physiotherapy and speech and language therapy teams. (see appendix 1). It is unlikely that the interventions outlined above would have increased her life expectancy or resulted in a significant change in management that would have generated a difference to the experience or quality of life for Ms Bright across the remaining 10 days of her life. However, they would have utilised over 280 hours of clinical staff time and Ms Bright would have required at least four slots in radiology and neurosurgery services. Reducing

unnecessary interventions and investigations increases the capacity of diagnostic services for other patients for whom there is a clinical benefit.

The landscape of cancer care is changing rapidly. Many patients - especially those with advanced progressing cancer - will require the help of healthcare professionals who have expertise in managing a range of problems, whether these are associated with the cancer itself or because of cancer treatment. ESC aims to bring those professions closer to the patients who need ESC most, at the right time.

In this instance the ESC pathway provided a better alternative for Ms Bright. She was able to benefit from the ESC team's expertise in managing the problems she was facing and was able to receive the care that was best for her at that specific point in her life.



2. Supportive care teams that work together

What was different for Ms Bright because ESC was available?

Our key principles:

1. Earlier involvement of supportive care services in cancer care
2. To reduce length of stay
3. Avoid unnecessary admissions and re-admissions
4. Lessen workload pressure on the acute floor
5. Reduce amount of unnecessary clinical investigations
6. To enhance quality of life for patients

The ESC team provided a swift, comprehensive, holistic assessment of Ms Bright's situation at the point of admission (including engagement with her family) within A&E.

They provided more than would routinely be included within the initial Emergency Department assessment process; a different emphasis and 'added value'.

Liaison occurred, between three teams without bureaucratic administrative processes being required; avoiding the usual delays that exist in the system.

ESC is a single point for contact with the family. 'Only having to 'tell the story once' so that this

could be shared in a timely way with key members of the teams involved in Ms Bright's care.

Providing reassurance and support for the family in this context is an additional benefit from ESC. Ms Bright's preferences could be considered from the very start of her interaction with the healthcare system and form the start point for the decision-making process. Patient advocacy and 'what matters to me' is delivered through the ESC team approach to engagement and collaboration with other clinical teams and the family.

The ESC team facilitated a much less distressing experience and much more seamless care for a vulnerable individual who could not advocate for herself or express her wishes in this context. They could focus less on the immediate acute management and more around building a holistic picture of Ms Bright, her situation, background; more on her wishes and expectations.

Ms Bright was able to spend 83% of her remaining life, from the point of arrival at ED until her death in a hospice and not in acute care in hospital. She was in an environment where her family had better access to her in a supportive environment with fewer acute pressures and demands. She did not need to suffer any additional distress associated

CNS Rob: "We've had some really good feedback from the acute floor teams, and we are always greeted with a friendly face. The doctors and nurses are happy for us to get involved and enhance the patient's assessment and provide support for on-going treatment plans."

with respiratory infection and aggressive treatment or upheaval associated with tests and investigations. Her family did not have to face uncertainty whilst waiting for results and did not

Dr Ellie: "I think it's quite helpful that we're a supplementary team but not the main treating team. We approach people with a different mindset - we're not just looking at what we can do to reverse whatever's happening medically, although we can help support with that. We go with a supportive focus on what's important to patients and their families.

It's sometimes useful to be a little bit outside of the treating team as well. I think to have a bit more of an overview and to understand a bit more about patient journey - prehospital and what's going to happen when they leave hospital."

have to communicate with multiple sets of teams or manage different information and opinions. ESC reduced anxiety for her family around the daily challenges of sorting out discharge arrangements and protected them from the complexities around the discharge process from acute care - a part of the process that is recognised to create high levels of stress and anxiety for individuals and their families. In this instance ESC also meant family did not have to take time off work to attend MDTs or help social workers to resolve issues with care packages.

Being in the hospice enabled Ms Bright's family to spend time with her without the intrusion of hospital regimes, tests and

treatments. The ESC service ensured that she was in her preferred place of care with emotional support of her family and could have a good death.

Apart from the additional cost to the health service associated with acute admission to hospital, the family members involved in caring and supporting the patient during this time also incur costs; loss of income, car parking charges, phone calls (often to multiple agencies), and taking time out of work to join case conferences or making appointments to see the doctors or consultant.

The Impact of ESC on Ms Bright's family

Acute Care

Burdens
 Family need to call ward for information
 Costly care required for dependent (mother)
 Charges for visitor car parking
 Limited visiting times/work commitments
 Anxiety due to tests and interventions
 Complicated discharge planning



Benefits
 Patient is "safe" and has access to immediate medical care

Hospice

Benefits
 Patient is "safe" and has access to immediate medical care, but only if necessary.
 No more transfers to new locations.
 Reduced risk of hospital acquired infections
 No charges for visitor car parking
 Flexible visiting times
 Fewer staff to engage with
 Emotional, spiritual and psychological support
 A good death



Burdens
 Costly care will be required for dependent (mother)

How does ESC make a difference to the Trust? The impact on people

The ESC team support the acute oncology, palliative care and medical teams to assess health needs of patients with life limiting conditions who present to ED. They are an integral part of these teams and bring expertise and skills in patient engagement and conversation to establish what their wishes are in relation to investigations, treatment options and place of discharge and on-going care.

ESC can be offered to:

- Patients with treatable but non-curative malignant / non-malignant disease.
- Patients who have chronic, non-curable disease who exhibit a positive SPICT and/or Rockwood Clinical Frailty scores (Rockwood Score more than, or equal to 5).
- Patients admitted with symptoms arising from their systemic anti- cancer treatment (SACT).
- Those with newly diagnosed metastatic disease.
- ESC will accept referrals verbally and by phone.

CNS Katie: "Our main referrals will be to palliative care and acute oncology. The aim is not to pass on these patients and give these teams extra work, we see and assess each patient on behalf of the team and work with their Consultants and CNS's to ensure best outcome for the patient, ensuring there is a robust plan in place."

How does ESC make a difference to the Trust? The impact of ESC on the system

Enhanced Supportive Care is an initiative to promote the earlier implementation of supportive and palliative care within cancer care. *"Supportive care is the prevention and management of the adverse effects of cancer, and cancer treatment."* (MASCC - Multinational Association of Supportive Care in Cancer)

The team have really settled in on the acute floor and have formed relationships with the senior medical teams which have and will continue to be of great benefit to patients.

Dr Ollie Minton

The presence of the ESC team makes a difference on many levels. For Ms Bright, ESC meant that she avoided a prolonged spell – her last weeks of life – in an acute bed in hospital. Avoided being a strange place, with many uncomfortable procedures taking place daily, mostly preventative and focussed on managing her medical conditions and involving many different teams.

These are associated with costs. Whilst most costs are tied in with the bundles of care and block contracts it is still useful to unpick this and understand the breadth of impact that each ESC intervention can have.

By preventing a ten-day admission for Ms Bright, the ESC team enabled the Trust to;

- **Regain at least 19 hours of AHP capacity to use for other patients**
- **Regain 240 hours nursing capacity and one bed for use for another patient across 10 days**
- **Free up slots for at least 6 procedures and interventions at an (approx.) cost £1300**
- **Avoid complexities around initiating d/c planning to care home and a death in hospital.**
- **Avoid an admission to acute care, which could cost up to £4232**

Earlier intervention with palliative care patients is really important to allow patients and their families to plan for the future and manage expectations.

Palliative Care Consultant

We have noticed a marked improvement in length of stay, as patients are being investigated and plans are now put in place earlier in the patient pathway.

Acute Oncology Nurse

The application of the principles of ESC across BSUH through their ESC team, changed the approach from a conventional acute medical pathway to a more proactive, positive supportive bespoke one for Ms Bright. They promoted 'better supportive care' in what turned out to be her last days of life. They supported clinical teams, the patient and her family when making decisions around oncological treatments; helping a smooth transition to

best supportive care at a critical moment by creating opportunities for earlier conversations and planning of care resulting in the best outcomes for Ms Bright.

With time the impact of embedding ESC across the continuum of the pathways for cancer patients will mean that there will be fewer instances of Ms Bright's story. Because ESC;

- Will pick up patients earlier in their cancer pathway and provide earlier proactive support which will improve the management of symptom burden and consequently avoid triggering unplanned admissions.
- Will enable improved monitoring of patients via MCO and PROMs; detecting problems more quickly and responding to them promptly through a greater use of elective admissions rather than non-elective admissions.
- Will have a positive impact on A&E attendances generally. By improving coordination of the management of patients in the community; between oncology and palliative care, ESC will gradually facilitate a more planned approach to symptom escalation and more patients with clear plans for alternatives to acute admission via A&E. (saving approx. £126 per visit + capacity and resources in A&E and for paramedic services)



Therefore, there may be a gradual shift over time from the need to manage individuals with Ms Bright's experience in A&E, to one of managing a greater proportion of them proactively away from acute care. Subsequently, less ESC time being spent in A&E overall, and with a greater percentage of that time identifying other, new patients, earlier in their pathway, for whom earlier access to ESC may then provide a different experience and cancer journey.

There is now clear evidence that access to ESC has a significant impact for individuals on unplanned admissions in the last year of life, on duration of stay in acute care, and through more successful completion of chemotherapy regimens and management of symptom burden⁵. The BSUH ESC model and Ms Bright's story show how this ESC team are shifting patient experience positively towards these impacts, through their interventions in A&E alone. In this instance, for less than 5 hours of ESC team time.

This case study shows that alongside unquantifiable quality of life benefits for individuals and their families, ESC is making a difference to how services are used, and how teams work together at BSUH. These are an important but difficult to capture elements of the return on investment; the 'invisible benefits'

Return on Investment

A. Costs avoided due to Ms Bright accessing ESC

Costs Avoided £	Ms Bright	1 x Ms Bright per month	1 x Ms Bright per week
Acute care	5500	66,000	286,000

The cost of making ESC available to support Ms Bright was £125 (approx. 5 hrs clinical time funded through the ESC service) and for the hospice, a cost of £1100 whilst the savings generated to the system from that support exceed £5.5k.

B. Capacity regained per annum due to Ms Bright accessing ESC

Capacity regained	Ms Bright	1 x Ms Bright per month	1 x Ms Bright per week
Acute care - Hrs	270	3240	14,040
Bed days freed	10	120	520

In addition, the 5 hours of ESC service freed up 240 hrs of Nursing time, a bed for 10 days, and 16+ hours of AHP capacity for use with other patients. Modelling using Ms Bright's experience indicates that even with one individual a month the savings generated/ROI would cover 30% of the cost of the ESC service. One patient a week would more than cover the cost of the ESC service entirely.

C. Potential costs avoided for the system through ESC preventing admissions via A&E

Costs Avoided £	Ms Bright	1 x Ms Bright per month	1 x Ms Bright per week
Non elective admission	4232*	50,784	220,064
A&E	126	1500	65,00
Emergency services	286*	3432	14,872

The 'invisible' impact of ESC

Similarly, this would free up 3240 hrs capacity for staff – equal to more than 86 weeks of 1 WTE AHP/Nurse – in effect adding capacity of a further 1.5 members of staff to the workforce.

With positive benefits to A&E and emergency services from avoiding use of these services for ESC pts

D. Potential capacity freed up through ESC preventing avoidable admissions

Capacity regained	Ms Bright	1 x Ms Bright per month	1 x Ms Bright per week
Acute care - Hrs	270	3240	14,040
Bed days freed	10	120	520
A&E - hrs	8	96	416
Paramedic & emergency services - hrs	2	24	104

If there is the equivalent of Ms Bright every week, the savings would more than pay for the ESC service, free up over 14000 hrs of staff capacity (over 370 weeks of 1 wte Nurse/AHP - in effect adding capacity of a further 7 members of staff to the workforce.

With positive benefits to A&E and paramedics, freeing up their capacity/beds for other patients

Central to the success of the ESC team is building relationships with other teams on the acute floor as well as oncology & palliative care teams.

Their contribution and early involvement in assessing patient health needs, from the patient's perspective, using evidence based standardised frameworks, has made their role integral to care planning decisions whether it is ongoing treatment or discharge home or in hospice.

CNS Katie "Our knowledge is expanding on the job as we are assessing a wide range of patients at different stages of their disease. We are gathering a portfolio of services internal and external to ensure the patient is tied into the right service for them their families and carers."

The team has also gained in confidence and skills to represent the views of patients with clinical teams. Their intervention ensures that patients wishes about their care and treatment options are respected and acted upon.

The ESC team play a unique role, advocating for patients and supporting the clinical teams to arrive at decisions that respect the patients' wishes.



3. Cutting edge and evidence-based practice in supportive and palliative care.

Why ESC matters to Ms Bright

‘Supportive care teams should commit to ensuring that the care they provide is cutting-edge, with awareness of the latest available pain and symptom control treatments used in different stages of cancer care’.

Practical Steps: Summary of Key Principles

Right treatment at the right time – excellent pain and symptom control throughout treatment.	✓
The right treatments for managing pain and symptoms, including management of the side effects of cancer treatments, must be provided promptly.	✓
Treatments for managing pain and other symptoms must be appropriate to the stage of cancer, and, where possible (during anti-cancer treatment or clinical trials), be made in conjunction with the oncology team.	✓
Every effort should be made to ensure that the side effects of treatments for pain and symptoms are kept to a minimum – especially regarding the use and doses of opioid medication.	✓
High dose opioid therapy can be ineffective and be associated with adverse outcomes in chronic cancer pain. Clinicians should consider greater use of non-opioid analgesia, earlier use of interventional analgesia and where appropriate, non-pharmacological - particularly for patients who are undergoing anti-cancer treatment.	✓
Specialist pain and symptom control should be undertaken by the relevant supportive care teams who have the expertise and skill to manage difficult problems. Patients who are escalated to high doses of opioids should be promptly referred on to teams that have appropriate pain control expertise.	✓
Extrapolating the recent evidence in chronic non-cancer pain, the total daily dose of opioids should not be increased above 120mg oral morphine equivalent without either the patient demonstrating improvement in function and pain or first obtaining a consultation from a practitioner qualified in pain management.	

Dr Ellie: “We’re also trying to make sure that people have appropriate treatment escalation plans, and that they’ve had those difficult discussions earlier in their admission rather than having a very distressing discussion at the point that they are critically unwell, so hopefully getting those discussions in earlier and just normalizing that as part of the process of someone being admitted to hospital and they’ve got a life limiting condition.”

CNS Katie & Rob: “I think what we’re finding at the moment is that the beauty of Brighton is that acute oncology, palliative care and supportive oncology all sit in the same room. So, you know, we can kind of work pretty symbiotically. We were able to work on behalf of and with at the same time. Today I’ve been with acute oncology, but actually seeing patients from a supportive approach and using it as a 2 for one, almost with regards to things outside of the usual kind of framework. I have started making some inroads with the health and wellbeing coordinators in Macmillan starting in January. So, especially because there is a lot of isolation nowadays, we look at these patients more from a social holistic perspective well.”

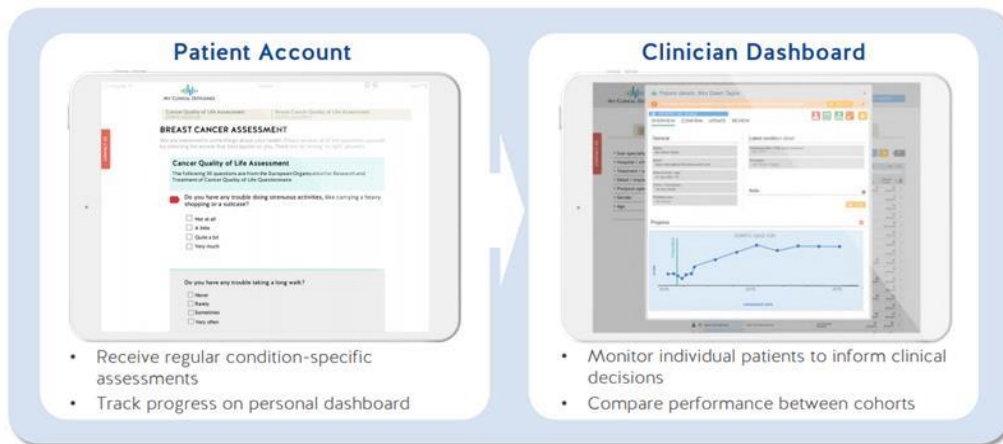


4. Technology to improve communication

How was technology relevant to Ms Bright's story?

A proactive approach to monitoring patients' quality of life

The ESC team use an app based platform, "My Clinical Outcomes" (MCO), which enables them to monitor patients' quality of life. Patients are sent automated reminders fortnightly via email to respond to 30 questions which are designed to collect information about health and wellbeing issues, such as appetite, pain, anxiety. Patients are also able to submit completed questionnaire as issues arise with their health or condition. This allows the patients' to be monitored regularly for as long as required and the ESC team can act or organise timely referrals to other teams to resolve issues raised, avoiding A & E



visits. The MCO platform generates a monthly report showing mean scores by different tumour types and a summary of symptom burden of patients. The team can also

get details of patient scores in specific areas e.g. out of 70 patients almost half reported being continually tired through their treatment.

The platform is also used by patients discharged back home or in care homes who are supported by community teams. The patient reported outcomes measures of quality of life allows the ESC team to monitor patients and ensure appropriate support and timely referrals are made to other specialist services to resolve issues.

In addition, the results generated by the programme can be used by the wider MDT supporting the acute oncology service. For example, the dietitians had noticed that all liver & pancreatic patients reported lack of appetite which the dietetic team can address for these patients. The programme gives insight into specific problems patients are experiencing and their current symptom burden. The programme has been established since September 2020 and the team are collaborating with the regional AHSN to analyse data and evaluate the service.

CNS Rob "Today I saw a patient who we've introduced to MCO too and he gets to the point where he's having some bleeding giving him symptomatic anaemia, and he presents acutely. But we can get him into a clinic for haemoglobin check, and potentially a blood transfusion afterwards on a regular basis, rather than a big long 4-5 day stay in hospital with his terminal cancer. We've now signed him up for MCO as well, so he can report symptoms himself as well. So, it's just using different ways of trying to monitor."

How does the use of technology by the ESC team streamline services and facilitate care?

In Ms Bright's story, the ESC team were involved in the first 24-48 hours to assess her needs and develop care plans to discharge her, in this instance to a hospice as appropriate. In situations where LOS exceeds beyond 48-72 hours, then oncology and palliative care team within hospital continue to care and treat patient as planned.

This is also made possible because the ESC team are based on the acute floor and get directly involved much earlier in the process i.e. when patients arrive. Currently the Oncology Team does not have a dedicated ward and therefore has patients distributed across various wards in the hospital. This builds in delays to their agility around reviewing patient needs and having timely conversations about discharge and care plans.

CNS Katie: "Because we're more present now on the acute floor, they're able to see us and refer straight away, or we're actually proactively picking up these patients and making plans for them and discussing with other teams. Acute oncology is really stretched across the hospital and their ward round is massive, and so we are able to actually see these patients and then liaise with their clinical nurse specialists and their doctors. Same as palliative care, it makes for a quick, seamless assessment and feedback to those doctors that the patient is under. Because there are long delays for patients as we know, waiting for specialist assessments."

Quality Outcome Measures

Reduction in Patient ED re-attendance and readmission rates that have been reviewed by ESCT.
 Acute Floor staff satisfaction with the service provided by ESCT
 Some method of capturing quality of experience of the patient's / those important to them who receive input from ESCT on the Acute Floor.
 Reduction in length of stay for patients with palliative and end of life care needs
 Improve patient experience and quality of life for patients seen by the ESCT at 6 months post implementation of service.
 Qualitative data will be collected from My Clinical Outcomes.
 Quality samples to continue throughout the 18-month programme.

Additionally, these patients are usually seen by junior doctors within the medical team who may be less confident around their experience and may wish to wait for the consultant to review the patient before progressing conversations and decisions. Therefore, having the ESC team member engaged in conversation earlier with patients who have life limiting conditions, who can undertake review enables care plan to be put in place more swiftly. The

review by the ESC team is holistic so it includes non-clinical needs, the individual's personal circumstances in addition to finding out what the patient wishes are about investigations, treatment options and place of care.

They share this information through a variety of routes including documentation as part of the ESC pathway to maximise engagement and minimise confusion and delay.

Documentation

HNAs are saved within a secure location on the shared computer drive, which will be readily available to ESCT staff to refer to directly. ESCT will complete ReSPECT documents where indicated

Onward Referrals

ESC liaise directly with, and update Primary Care Teams, Site-specific CNS groups, Acute Oncology services and Palliative Care teams

ESC complete onward referrals to Community Palliative Care Team and relevant external organisations where indicated

Future Treatment

Input future treatment and care plans onto Intelligence Base Information System (IBIS, SECAmb database)

input to Outpatient and Virtual clinics for patient follow up to be determined in Phase 3 of project, once established team will identify those patient to be reviewed