A short report examining the introduction of routine use of patient reported outcome measures in a mixed oncology population

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Funding for this project was through a grant for the development of an Enhanced Supportive Care service in Oncology at University Hospitals Sussex from NHS England/Improvement and funding of the My Clinical Outcomes platform was from the Sussex Cancer Fund.
Dr Tim Williams is the CEO of My Clinical Outcomes & other digital platforms are available.
There are no other conflicts of interest for any of the authors.

ETHICS & GOVERNANCE:
This project was designed and approved as a service evaluation via the Enhanced Supportive Care Project commissioned by NHS England/Improvement. The project was processed using NHS HRA REC decision tool and was found not to require NHS REC review.

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OM, ST & ES conceived the idea for the project
All were included in writing and approving the final manuscript

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ABSTRACT:

Purpose: 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.
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 email 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: 324 patients completed at least 1 assessment. The median number of assessments completed by each patient was 8. 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 in providing 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.

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 in improving 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 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 1 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 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 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.

METHODS:

Study setting:

The Sussex Cancer Centre at the Royal Sussex County Hospital (RSCH) offers Tertiary Cancer Services to a population of approximately 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 RSCH 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 utilise *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 (22/09/2020 to 07/06/2021). 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 approximately 20% of eligible patients registered.

Study assessments:

Patients were invited to register with *My Clinical Outcomes* (MCO) – a secure online platform for the collection of electronic PROMs, inputting their tumour type and treating consultant. They were prompted by email to complete 3 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 focussing 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 5 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 patient's assessments. The research team agreed 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, however 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:

326 individual patients registered during the study period. 324 patients completed at least 1 assessment over 6 different hospital sites. Of these 51% identified as male, and 49% female. Median patient age was 69 (interquartile range 59 – 75). The median number of assessments completed by each patient was 8 (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 demonstrates 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 be development of toxicity and disease progression).

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 1: Number of patients registered 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 1 assessment

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

[INSERT FIGURE 1]

Figure 1: examples of changes over time in EORTC QLQ-30 scores

Overall, the symptom that caused the most significant burden to patients' experience was fatigue and impact 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 demonstrates 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 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 and prostate are the most common cancer types in the UK[16], which is reflected in our study population. Lung and bowel cancer are the 3rd and 4th most prevalent in the UK, although represented only 2% and 1% respectively of patients in our data set. 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 disease and 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 demonstrates 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 & neck and haematological malignancies which complicates 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.

Whilst 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 COPD 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 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 programme 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.

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 and this will negatively impact on engagement. However, tailoring of questionnaires to use modules or questions specific to diagnosis or treatment type may improve 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. 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. Whilst 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 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 whilst 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.

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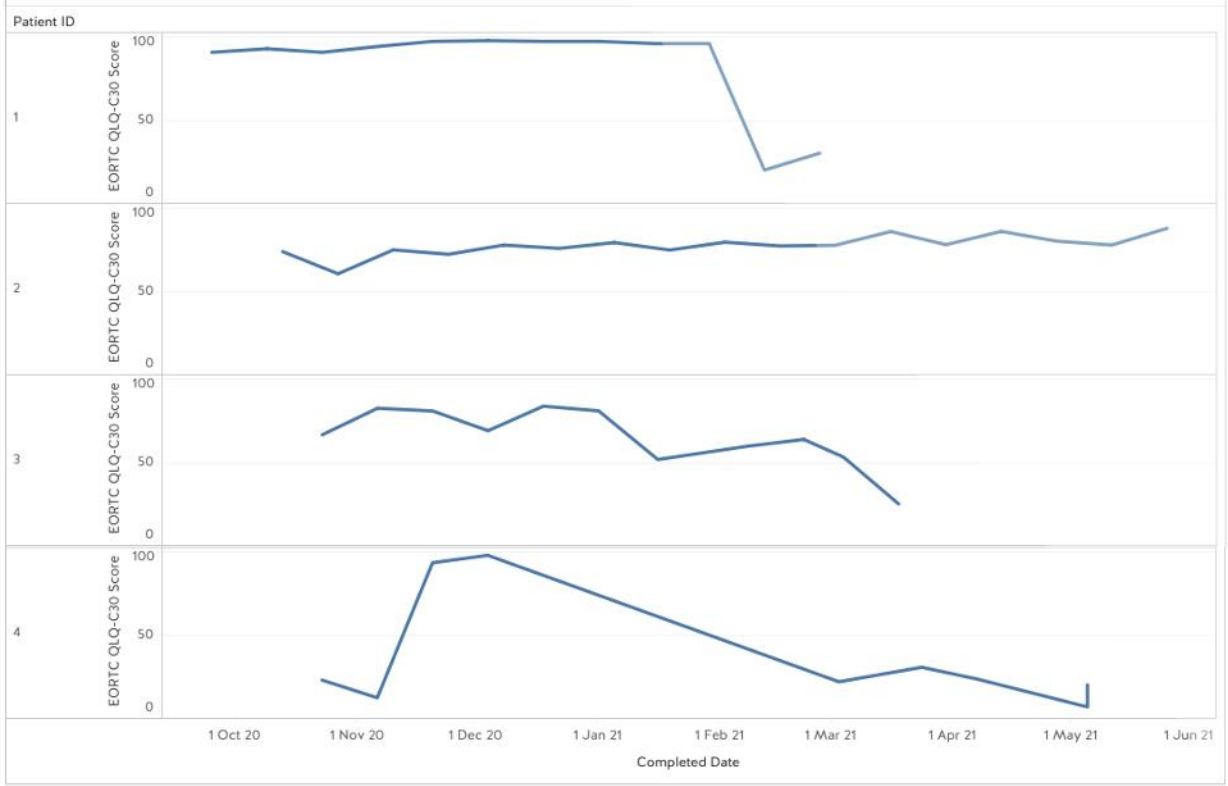
EORTC QLQ-C30 - Response Detail

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

My Clinical Outcomes

Patient-Level Longitudinal EORTC QLQ-C30 Scores



Source: Extract from MCO Data Visualisation Package. Analytics data only for patients validated by a BSUH hospital staff member.