Original Article

Online symptom monitoring for lung cancer patients receiving systemic therapy: a feasibility implementation project

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Background: Modern systemic anti-cancer therapies have resulted in an improved prognosis for lung cancer patients. However, their complex toxicities require close monitoring. An existing e-Health platform called eRAPID (Electronic patient self-Reporting of Adverse events: Patient Information and aDvice), enables patients to report symptoms and receive automatic severity-dependent advice to self-manage or contact the hospital. Symptom data is available in real-time for clinicians in the patients' electronic patient record (EPR). The feasibility study aimed to implement eRAPID for symptom/toxicity monitoring of lung cancer patients during and after systemic therapy. Primary outcomes were recruitment and consent rates, attrition rates and adherence to symptom reporting. Secondary outcomes were: (I) type, frequency, and severity of self-reported symptoms; (II) activated clinical algorithms for patient advice; and (III) patient and staff acceptance and views.

Methods: Consecutive patients starting systemic therapy were recruited and followed up for 12-months. Participants joined Cohort 1 (online access, reporting weekly from home) or Cohort 2 (no online access, completing before appointments every 4–6 weeks with assistance). Patients completed symptom reports, designed with the lung clinicians, plus 3 monthly quality-of-life questionnaires (EuroQol-5 dimensions). Descriptive analysis was employed for the quantitative outcomes. Semi-structured interviews and online feedback gathered views from a subset of patients and clinicians, using thematic framework analysis. Study project registration number: NCT04324437.

Results: Between August 2020 and July 2022, eighty-five patients were eligible, 43 (50.6%) consented, 33 Cohort 1, 10 Cohort 2. The attrition rate was 65.1% (28/43) primarily due to disease progression. For all patients, a total of 841 symptom reports were generated. For Cohort 1, the mean weekly adherence for symptom reporting was 68.9% (range, 50–70%). The most reported symptoms were fatigue (77%), physical limitations (76%), pain (60%) and shortness of breath (59%), but they were mainly mild. The clinical algorithm generated 56 notifications to the clinical team for severe symptoms (6.7%, 56/841), with physical limitations and rash most common. Three-monthly adherence to quality-of-life questionnaires was 60–90%. Patient and staff feedback (n=14 and n=9) revealed reassurance and confidence from patients in self-managing side-effects. Although clinicians did not always discuss the reported symptoms, patients felt more connected to their healthcare team. Clinicians valued eRAPID for tracking symptoms, planning consultations, making timely clinical decisions and improving patient relations.

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Conclusions: The eRAPID approach was accepted by half of the patients who were eligible to take part. There was good adherence over time, and willingness to complete 3-monthly quality of life measures. Clinicians and patients supported the intervention for routine practice but required further investment and support from the hospital to make the symptom monitoring sustainable.

Keywords: Patient reported outcome measures (PROMs); health-related quality of life; lung cancer; systemic anti-cancer treatment; implementation

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Introduction

Lung cancer is the most diagnosed cancer globally and is the third most common cancer in the UK [13% of all new cancer cases (2017–2019)] (1). Mortality rates due to lung cancer are higher than any other cancer in both the UK (20% of all cancer deaths) and worldwide, with global mortality projected to reach 3 million by 2035 (2). One-year survival of 18,653 patients with lung cancer in England and Wales is 49.6% according to the 2023 National Lung Cancer Audit (3).

Most cases are diagnosed at Stage 3 and 4 when treatment options are limited to non-curative systemic therapy (traditionally chemotherapy) and palliative radiotherapy. Recent advances introduced a range of targeted systemic anti-cancer treatments (SACT): immunotherapy, tyrosine kinase inhibitors (TKIs), monoclonal antibodies, and antibody-drug conjugates (ADCs), which offer patients personalised therapies, based on molecular profiles (4). These tailored treatments, though not curative, have improved prognosis for patients with later stages of the disease (5). However, the severity and range of side-effects of these innovative treatments require close monitoring, particularly in this usually frail patient population due to significant disease symptoms and other concurrent medical co-morbidities. In addition to their impact on patients' health-related quality of life (HRQoL), the adverse reactions to SACT may be serious and potentially fatal, leading to unplanned hospital admissions and/or immediate management (6). Thus, improved survival with innovative treatments has led to an increased burden on already stretched health services (7).

During consultations, patients may not accurately recall symptoms and oncologists cannot always precisely assess toxicities longitudinally. Real-time rather than retrospective management of toxicities can be supported using data gathered via patient-reported outcome measures (PROMs). PROMs are measures, based on a "report that comes directly from the patient about the status of a patient's health condition without amendment or interpretation of the patient's response by a clinician or anyone else" (8). PROMs include physical symptoms, treatment toxicities, physical or emotional functioning, and/or HRQoL. A growing

Highlight box

Key findings

- This real-world implementation study demonstrated that online symptom monitoring is feasible for around 50% of consecutive advanced lung cancer patients starting systemic treatment. A quarter of those chose to report from clinic, due to a lack of internet access. Attrition was relatively high at 65% due to disease progression. Adherence to symptom reporting and 3-monthly health-related quality of life questionnaires was good, without a decline over time. Symptoms reported online were predominantly of mild/moderate severity, generating patient advice. Only 6.7% of all reports generated notifications to clinicians and patient advice to contact the hospital. Patients reported an increased ability to self-manage side effects. Clinicians noted improved patient interactions and more timely clinical decisions for patients with worsening toxicities.

What is known and what is new?

- Web-based symptom monitoring has been associated with enhanced quality of life, treatment tolerance, reduced emergency room visits, and survival benefit in advanced cancers. In lung cancer patients, regular reporting of PROMs after disease response identified earlier relapses, leading to more timely treatment and improved overall survival. Implementation in routine practice remains a challenge. This study provides data on real-life acceptability and benefits for patients and clinicians.

What is the implication, and what should change now?

- Choosing the patient population and treatment setting (during and after therapy) is important to maximise the benefits for patients and services. Dedicated support from hospital stakeholders is required to ensure the sustainability of online symptom monitoring.

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number of randomised controlled trials (RCTs) showed that online symptom monitoring and collection of electronic PROMs (ePROMs), can improve symptom control, patient well-being, patient care, and support doctor-patient communication (9-12). Web-based symptom assessments have been associated with enhanced HRQoL (13) and treatment tolerance, reduced emergency room visits (11,14), and improved survival benefit in advanced cancers (12).

In lung cancer patients, regular reporting of PROMs after disease response identified patient concerns and earlier relapse, leading to timely diagnosis of recurrence and improved overall survival (10,15). Similarly, implementation of ePROMs was linked to less problematic symptoms in a cancer assessment unit and more referrals to allied health services, highlighting the potential of ePROMs in enhancing the routine care of lung patients (16).

Our research in the Leeds Cancer Centre also demonstrated better symptom control and self-efficacy, without increasing hospital workload in breast, ovarian and colorectal cancer patients during chemotherapy, when an eHealth intervention was added to their usual care. The eHealth platform, known as eRAPID (Electronic patient self-Reporting of Adverse events Patient Information and aDvice, study project registration number NCT04324437), enables patients to report symptoms online and depending on symptom severity, to receive automatic self-management advice or hospital contact. Symptom data were available in real-time for clinical staff in the patients' electronic patient record (EPR) (13,17).

Patient-centred care, symptom reporting and use of ePROMs integrated within the EPR are now recognised as a cost-efficient approach to monitor and support cancer patients during and after treatment (18). However, many challenges to routine ePROMs use in cancer care exist, related to administration, stakeholder engagement, resourcing, workflow integration and technology (19). There is a need to investigate optimal ways of implementing electronic monitoring systems as part of standard care (20).

This feasibility implementation project aimed to introduce and evaluate the online symptom monitoring intervention (eRAPID) in the routine care of lung cancer patients during and after systemic therapy. The primary outcomes were recruitment and consent rates, attrition rates, and adherence to symptom reporting and HRQoL measurement. The secondary outcomes were the description of the type, frequency, and severity of self-reported symptoms; frequency of activated clinical algorithms and notifications; and evaluation of patient and staff acceptance and views on the utility of online symptom reporting, with the goal to refine the intervention and roll-out in patient care. We present this article in accordance with the SQUIRE reporting checklist (available at https://jtd.amegroups.com/article/view/10.21037/jtd-2026-0602/rc).

Methods

Setting, participants and study design

This was an interventional, prospective real-world implementation project conducted at Leeds Cancer Centre, Leeds, United Kingdom. Consecutive English-speaking patients with a diagnosis of lung cancer were eligible when starting palliative SACT, including chemotherapy, TKIs or immunotherapy with checkpoint inhibitors. Time since diagnosis was not included in the selection criteria. Exclusion criteria were patients receiving adjuvant chemotherapy, best supportive care or displaying overt psychopathology or cognitive impairment. Patients in clinical trials were not excluded. All clinical staff involved in the delivery of patient care were included and comprised cancer clinical nurse specialists (CNSs), advanced nurse practitioners (ANPs), and oncologists.

Participants were asked to complete symptom report questionnaires on a regular basis, plus quarterly HRQoL questionnaires, for a total period of 12-months using QTool, the patient-facing element of the eRAPID platform (13). As it was anticipated that many patients may not have internet access, the project design allowed patients to self-select into one of two groups according to online accessibility. Cohort 1 consisted of patients with online access who completed online ePROMs weekly (and/or when feeling unwell), away from the hospital. They received a user-manual at study commencement and weekly completion reminders via SMS or email. Patients without online access joined Cohort 2 and completed PROMs before each clinic visit (every 3, 4 or 6 weeks, dependent on SACT schedule) with help from the clinical/research team, if needed. They received a symptom self-management booklet through the post at study entry (see *Figure 1*).

All eligible patients were identified by the CNSs at the multi-disciplinary team meetings when a recommendation for SACT was made. The clinical team approached patients about the research following their clinical consultation. The researcher followed up to confirm participation, registered the patient, and provided a username and password to log in and consent. Demographical and clinical characteristics

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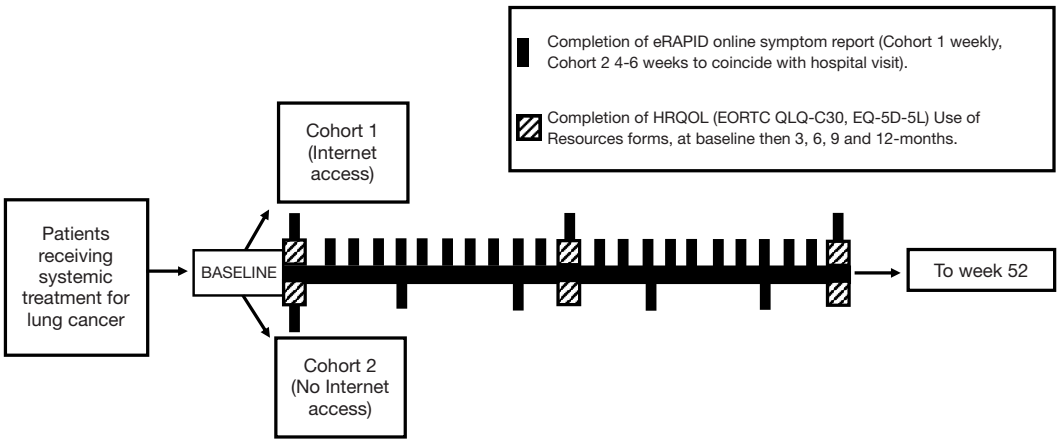


Figure 1 Project diagram including symptom and HRQoL reporting. Adapted from Holch *et al*. 2023 (21) under CC BY 4.0 license. EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30; EQ-5D-5L, EuroQol 5-dimension questionnaire, 5 levels; eRAPID, Electronic patient self-Reporting of Adverse events: Patient Information and aDvice; HRQoL, health-related quality of life.

were collected at baseline.

The study was conducted in accordance with the Declaration of Helsinki and its subsequent amendments. The study was approved by East Midlands-Leicester South Research Ethics Committee (20/EM/0026, 5th March 2020) and informed consent was obtained from all individual participants. The project was registered on ClinicalTrial.gov (identifier: NCT04324437).

Procedures

Usual care

The lung cancer team who supported the study comprised five oncologists, one surgeon, six CNSs, one CNS support worker and two ANPs. During weekly multi-disciplinary meetings, lung cancer patients potentially suitable for palliative SACT were identified. These patients were reviewed by an oncologist to assess their fitness for the recommended treatment. Verbal and written information was given on expected adverse events (AEs), how to manage them, when and how to contact the hospital, including out-of-hours. Patients who consented to SACT attended the cancer chemotherapy day unit for administration of intravenous treatments or took the oral therapy at home.

During SACT, patients are reviewed prior to each cycle by an oncologist or CNS to evaluate toxicity and/or disease response. SACT treatments can be modified due to the severity of AEs. During working hours, lung cancer patients can call and receive support from a team of experienced CNSs. Out-of-hours, acute medical problems are managed via dedicated acute oncology services, providing a 24/7 hotline for phone calls, and emergency admissions directly to the oncology department. Modification to this usual care was necessary during the Coronavirus Disease 2019 (COVID-19) pandemic.

Intervention

eRAPID, a complex eHealth intervention, was added to usual care in this study. eRAPID included online self-reporting of disease-related symptoms, treatment-related side-effects and HRQoL. *Figure 2* shows an overview of eRAPID active components (*Figure 2A*), with screenshot examples of patients' and clinicians' views (*Figure 2B,2C*). The self-reports were immediately available within the EPR to be used by the oncologist and CNS. The clinician-facing program of the eRAPID platform, called PROMPT (Patient Reported Outcome Measures Pathway Tracking), was integrated within the EPR and results were accessible from an individual's medical record or via the PROMPT uniform resource locator (URL) (22). Symptoms were viewable in either tabular or graphic format with severity indicated by a traffic light system, with clinically significant severe symptoms highlighted in red (*Figure 2C,2D*). A clinical algorithm was developed jointly with the lung team to determine the content of the automated severity-dependent advice to the patients (13). For severe and clinically relevant symptoms, all patients were instructed to contact the 24-hour acute oncology service hotline. This

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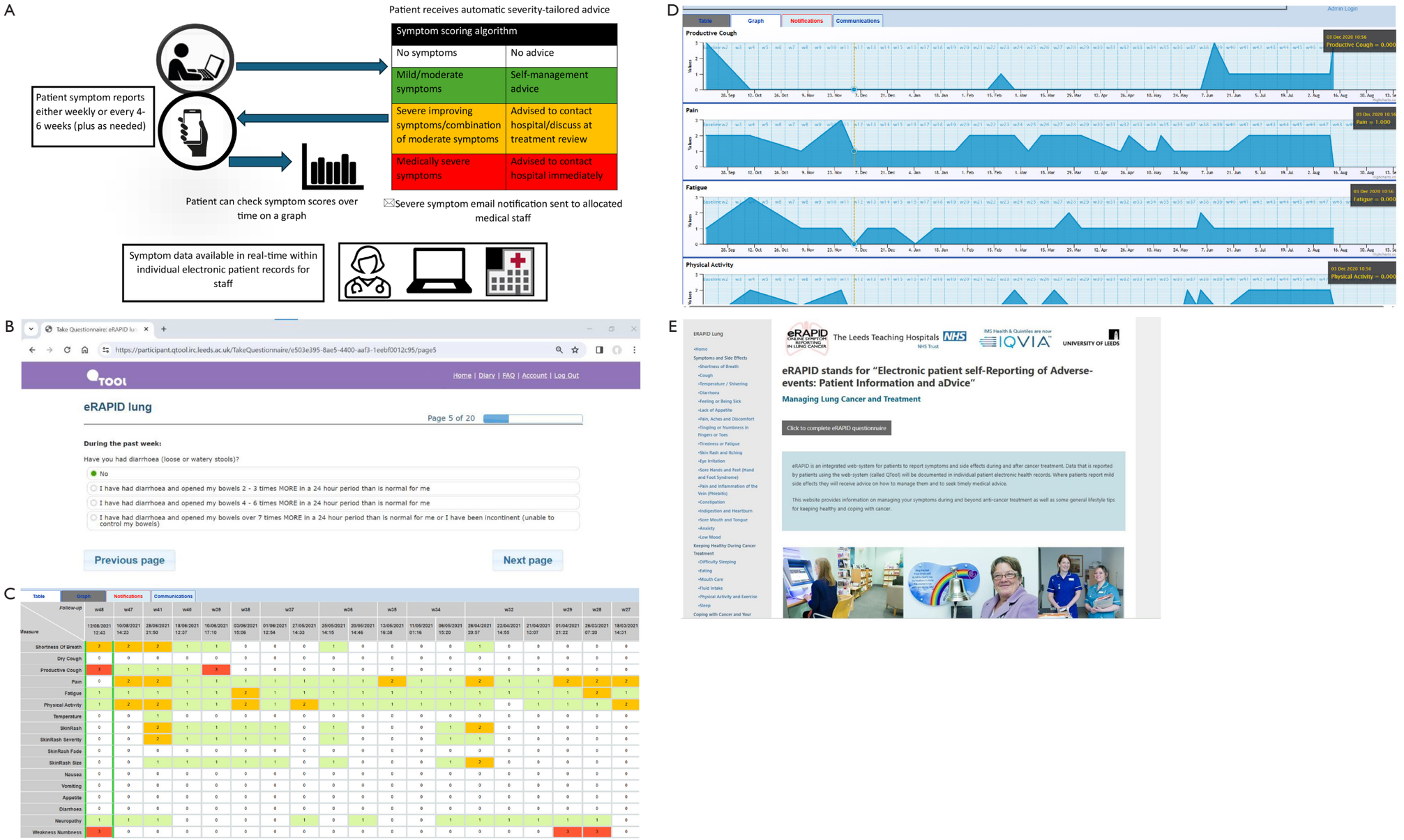


Figure 2 Overview of the eRAPID intervention. (A) Active components of eRAPID intervention. (B) Patient view of a symptom item on QTool, the patient-facing element of the eRAPID platform. (C) Clinician view of the patient symptom self-reports from within the individual's electronic patient records (table format). (D) Clinician view of the patient symptom self-reports from within the individual's electronic patient records (graph format). (E) Example screenshot from the eRAPID Lung website homepage. (A) was adapted from Holch et al. 2023 (21) under CC BY 4.0 license. eRAPID, Electronic patient self-Reporting of Adverse events: Patient Information and aDvice.

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advice was generated by the algorithm within the eRAPID software and displayed on screen, including the contact telephone number. Simultaneously, an email notification highlighting severe symptoms was sent to key allocated healthcare professionals (HCPs) who contacted the patients. Patients were not informed of notifications, so they did not anticipate direct HCP follow-up. For mild to moderate side-effects, Cohort 1 patients received immediate, automated, tailored self-management guidance to deal with their symptoms with access to more detailed information on the eRAPID website (*Figure 2E*). The website could be used outside of completions as and when needed. Cohort 2 patients were directed to appropriate advice within their self-management booklet and similarly the booklet could be used as and when required. Patients in Cohort 1 were asked to report weekly during and post-treatment for 12 months (52 weeks). Reminders to complete the eRAPID questionnaire were sent via email or text message. It was anticipated that Cohort 2 patients would complete via an iPad in clinic, however adaptations were made due to COVID-19. As clinic appointments were predominantly over the telephone, the clinical/research team telephoned the patient and completed the online questionnaire over the phone prior to their hospital appointments.

Content of online symptom monitoring (eRAPID lung questionnaire)

The content of eRAPID was originally co-designed with the help of patients and clinicians based on Common Terminology Criteria for Adverse Events (CTCAE) Version 4 for monitoring during chemotherapy for breast, colorectal and ovarian cancer (23). This existing library of eRAPID items was used to select lung cancer-relevant symptoms and treatment side-effects and to identify missing items. A literature review was conducted investigating the disease symptoms and common AEs of lung cancer chemotherapy regimens, immunotherapy and TKIs. Several oncologists reviewed the identified issues and selected disease-related symptoms, treatment side-effects and indicators of disease progression pertinent to monitoring for patient care. Five missing symptoms were highlighted (mainly related to immunotherapy toxicity), leading to the creation of new items. These were: Cough (Dry/Productive), Weakness and numbness, Skin rash, Itching, and Eye irritation. Beyond standardised items, free text boxes were included for patients to add other symptoms and their severity. The selected items were reviewed in consultation with key staff and patients to agree on the severity levels and develop the algorithms for patient advice and notifications. This procedure resulted in the patients being asked 15 mandatory symptom questions [Shortness of breath, Cough (Dry/Productive), Temperature, Diarrhoea, Appetite, Nausea, Vomiting, Pain, Neuropathy, Weakness and numbness, Fatigue, Physical activity, Skin rash, Itching, and Eye irritation] and a list of seven optional multi-selection items (Sore hands or feet, Phlebitis, Constipation, Indigestion or heartburn, Sore mouth or tongue, Low mood, and Difficulty sleeping).

Details and examples of severity grades, algorithms and patient-facing delivery are included in Appendix 1. The patient self-management advice was collated from existing local patient information, available local supportive services and reputable national web-resources (Roy Castle, NHS, Macmillan Cancer Support, Cancer Research UK).

Patient and clinician training

Cohort 1 patients received one-on-one training from a researcher on how to access the eRAPID online system. They were given an eRAPID 'postcard' with a unique username and password, as well as a step-by-step user manual including contact numbers for technical problems. They could access at any time the eRAPID questionnaire, self-management advice, and more detailed web-based advice. Cohort 2 patients completed over the phone with a research/clinical team member and were directed to appropriate advice within their self-management booklet, which was posted at study entry.

Several approaches for clinical staff training, engagement and education were followed including one-on-one and/or group training sessions by the research team to encourage use of eRAPID (24). Oncologists received training in accessing and interpreting patient symptom data in PROMPT and were asked to use and discuss the information during consultations, but were not provided with specific recommendations for actions. All six members of the CNS team were trained in accessing patient notifications and documenting action taken. Short instructions for accessing the self-reports in the EPR were printed, accessible in clinical areas, and emailed to support learning. At each clinic, the research team made treating oncologists or nurses aware of patients participating in eRAPID, reminding them to review eRAPID responses in the EPR. Training logs assisted researchers in tracking training for new clinical staff and refresher training as and when required. All clinical staff received eRAPID training

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certificates, which although not continuing professional development (CPD) accredited, could be used as supporting documentation in appraisals and nursing revalidation. Training materials and certificates are in Appendix 2.

HRQoL measures

In addition to frequent weekly symptom and AE monitoring, it was examined whether it would be feasible to include standard HRQoL questionnaires at less frequent intervals, as a global measure of treatment impact and effectiveness. This feasibility question was anticipated to be of interest from the perspective of real-world data projects where standard HRQoL measures would be useful for comparison purposes. HRQoL was assessed at five time points (baseline and then 3-monthly) using two instruments:

EQ-5D-5L

The EQ-5D (EuroQol 5-dimension) questionnaire is a widely used, standardized instrument for measuring health utility, assessing five key areas: Mobility, Self-care, Usual Activities, Pain/Discomfort, and Anxiety/Depression (25). Each dimension has 5 levels: no problems, slight problems, moderate problems, severe problems and extreme problems. The digits for the five dimensions can be combined into a 5-digit number that describes the patient's health state for health utility measurement. EQ-5D also has a self-rated health scale on a vertical visual analogue scale (EQ-5D VAS), ranging from 100 'The best health you can imagine' to 0 'The worst health you can imagine'.

EORTC QLQ-C30

The EORTC QLQ-C30 (European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30) is a widely used measure in clinical trials, assessing HRQoL of cancer patients. It has 30 questions with 5 functional scales (cognitive, emotional, physical, social, and role), 9 symptom scales (appetite loss, constipation, diarrhoea, dyspnoea, fatigue, financial difficulties, insomnia, nausea and vomiting, and pain), and one Global Health Status/HRQoL scale [two items: ranging 1 (very poor) to 7 (excellent)] (26). A summary score has been recommended based on higher order modelling (27), which has been shown to be a prognostic tool for survival in a range of cancers in real-world data (28). This paper reports only the summary score and the Global Health Status/HRQoL results for brevity.

Statistical analysis

Sample size

As this was an implementation feasibility study, the total number of recruited patients, and number per cohort, were not stipulated. The project planned 12 months of recruitment, aiming to identify and approach all consecutive eligible patients, with subsequent 12 months of follow-up.

Quantitative data collection and analysis

The primary outcomes of recruitment, consent and attrition rate were evaluated using the study management database. Patient adherence to online reporting and the descriptive analysis of type, frequency, severity of self-reported symptoms and frequency of activated clinical algorithms used data downloaded from the online eRAPID software.

Attrition rate was defined as the percentage of participants who withdrew, dropped out, or were lost to follow-up before completing the study at 12 months (calculated as the number of participants lost/total number of participants consented).

Patient adherence to online reporting was examined by:

(I) Proportions of expected patients completing the online reports per protocol once a week or quarterly for EQ-5D and EORTC QLQ-C30 (adjusting for withdrawals and deaths).

(II) Individual patient adherence, calculated as the completed online reports per patient divided by the number expected per protocol.

Separate and combined analyses within the two patient cohorts were planned. However, the above calculations were possible only for Cohort 1. In Cohort 2, the expected number of completions was variable due to the different treatment schedules and only a small number of patients joined the cohort. Therefore, a descriptive analysis was done for individual patients.

Descriptive analysis of the online symptom reports, as well as the HRQoL questionnaires, was performed (means and standard deviations) and presented as graphs over time.

Qualitative data collection and analysis

The secondary outcomes were patient and staff acceptance and views on the utility of online symptom reporting, with the goal to refine the intervention and roll-out in patient care. Qualitative feedback from patients and staff was obtained via semi-structured interviews and an online survey.

Patient interviews were planned with approximately

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12 patients based on purposive sampling at different stages of using eRAPID (either 2–6 months experience or 6 months or longer) from Cohorts 1 and 2. To achieve comprehensive feedback, regular completers and less compliant patients were both targeted. Relevant topics were covered during interviews, addressing experiences of using eRAPID and perceived impact on patient care. The interview guide can be found in Appendix 3.

Study feedback was also obtained via an online survey containing Yes/No questions and added free text commentary covering clinical interactions, usefulness of the symptom monitoring and self-management advice, and suggestions for improvement. Details of the questions asked can be found in Appendix 4.

Staff feedback was planned at two time points with five clinical staff involved in eRAPID implementation (n=3 oncologists, n=2 CNSs). Interim feedback, collected 4–6 months after study commencement, was obtained via an online survey with optional commentary concerning patient interactions, usefulness of the eRAPID system, and suggestions for improvements. The online feedback can be found in Appendix 5. The resulting feedback was used to implement any changes to the intervention. End of study feedback was obtained via semi-structured interviews, which covered questions around the usefulness of ePROMs, usability of software and perceived value and use of patient-reported data within clinical practice. The interview guide is listed in Appendix 6.

Interviews were conducted by four researchers (A.G., S.R., C.B., and R.P.), with analysis undertaken by two researchers (A.G., S.R.) using thematic framework analysis (29). Researchers took detailed notes during and after interviews, including direct quotes from patients. The *a priori* framework was based on previous qualitative analysis of eRAPID during chemotherapy (30). The main themes informed the interview schedule and the online survey. The researchers worked collaboratively, following the five phases of framework analysis: familiarisation, framework construction (mindful of any emerging themes to be added iteratively), coding, charting, mapping and interpretation (29). The researchers met regularly to discuss the codes, coding examples and sub-themes, as well as resolving queries. Both parties became accustomed to the data, and an iterative process was adopted to refine and hone the coding framework until thematic saturation was achieved (no new themes emerged). The free text from the online survey was collated, assessed, and summarised by two researchers under the coding framework developed from the interview analysis.

Impact of COVID-19

The project ran during the COVID-19 pandemic, including two lockdown periods. In line with guidance and social distancing rules, the usual care oncology practice changed with most consultations moving to telephone assessments. Only new patient consultations were face-to-face to allow assessment of fitness for treatment. This shift to remote care made recruitment difficult as invitations to participate required telephone contact by the CNS team. The planned Cohort 2 in-clinic completions of eRAPID on iPads had to be replaced by an interview style telephone completion. The researchers read aloud to the patient the automated advice and directed them to the provided booklet.

The planned qualitative interviews with patients in a private hospital room were not offered, as patients were immunocompromised. Patient feedback was gathered via interviews over the telephone and an online survey using QTool. For the same reasons plus reduced staff resources, interim staff interviews were replaced with electronic feedback via QTool. End-of-study staff interviews were conducted face-to-face in line with social distancing measures.

Results

Recruitment, consent and attrition rates

Between August 2020 and July 2022 inclusive, 192 patients were identified (*Figure 3*). Eighty-five patients were eligible, of whom 42 declined participation (49.4%, 42/85). Ethical approvals of the study did not allow the collection of demographic or clinical data from patients who declined to participate. Forty-three patients were enrolled with a consent rate of 50.6% (43/85) (33 Cohort 1, 10 Cohort 2). Two Cohort 1 patients switched to Cohort 2 as they were unable to secure IT assistance from a family member. The 12-month follow-up was completed in July 2023.

The baseline demographic and clinical characteristics are presented in *Table 1*. There was an almost equal number of male and female participants, with predominant diagnosis of non-small cell lung cancer (NSCLC). Although comparison between the two cohorts was not intended and may be flawed due to the small numbers, it should be noted that patients in Cohort 2 were older, only 1 had university or professional education (as a proxy for socio-economic status) and were retired.

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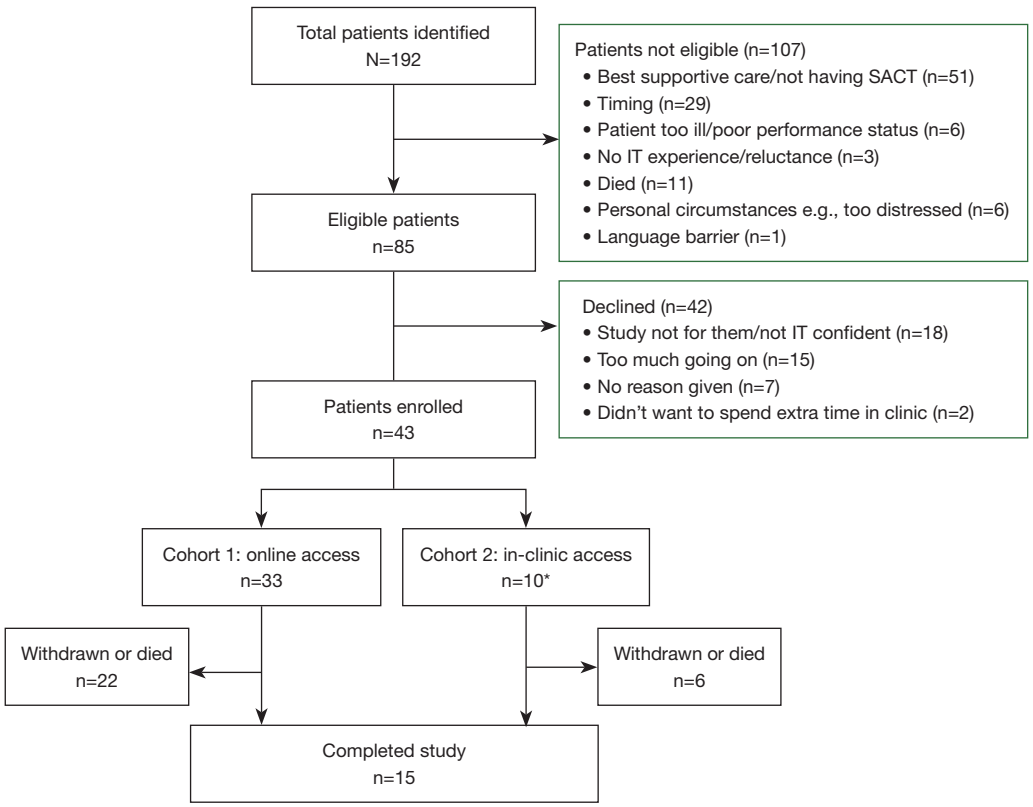


Figure 3 Recruitment flowchart of the eRAPID project. *, includes 2 patients who switched from Cohort 1 to Cohort 2. eRAPID, Electronic patient self-Reporting of Adverse events: Patient Information and aDvice; SACT, systemic anti-cancer therapy.

The attrition rate was high at 65.1% (28/43 participants): 10 participants died within the follow-up period, seven stopped treatment and moved to best supportive care, nine patients actively withdrew (felt ill, no time, too tired, treatment too complex), and two were withdrawn by clinicians (became too ill).

Patient adherence to eRAPID online symptom reporting

A total of 841 symptom reports were completed during the study period by 43 patients; 775 were scheduled and 66 were unscheduled. In Cohort 1 patients, per protocol adherence to the eRAPID reports from week 1 to week 52 was between 50% and 70%, with a median of 61%, mean of 68.9% (*Figure 4A*). No pattern over time was observed; adherence remained similar towards week 52, but the number of contributing patients was smaller due to patient attrition. When looking at individual patients, 9 completed ≥80% of the expected reports, and 5 completed <20% of the expected (*Figure 4B*).

The adherence to completing the quarterly HRQoL questionnaires was relatively high, 80–90% at baseline and month 9 (after finishing chemotherapy), and around 60% at the other time points (*Figure 5A*). On an individual level, 13/33 patients completed all forms; however, 2 patients did not complete any (*Figure 5B*). These results suggest that it is acceptable for patients to complete both weekly online symptom reports and HRQoL measures less frequently.

In Cohort 2, adherence to the symptom reports was high (see *Table 2*) as the research/clinical team ensured all patients were called prior to their clinical appointment to complete over the telephone. It was difficult to accurately ascertain the number of expected reports as it was dependent on treatment schedules. The number of expected completions was therefore based on the number of systemic therapy cycles, but for three patients, this resulted in calculated adherence >100%. On an individual level, 5/10 patients completed all expected times and the other 5 completed between 50% and 80% of expected. The completion of HRQoL questionnaires was high: at baseline 10/10 (100%), 3-month 7/9 (78%), 6-month 5/7 (71%), 9-month 5/6 (83%), 12-month 5/5 (100%).

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Table 1 Baseline demographic and clinical characteristics of the patients

Characteristic	Cohort 1 (N=33)	Cohort 2 (N=10)[†]	Total (N=43)
Age at baseline (years)			
Mean (SD)	63.6 (10.06)	72.2 (4.71)	65.0 (9.76)
Median (interquartile range)	65 (57–72)	71 (69–74)	69 (59–72)
Range	36–78	65–82	36–82
Sex, n (%)			
Male	18 (55)	5 (50)	23 (53)
Female	15 (45)	5 (50)	20 (47)
Education, n (%)			
Basic school education	18 (55)	6 (60)	24 (56)
Beyond basic school education	3 (9)	3 (30)	6 (14)
University or professional education	12 (36)	1 (10)	13 (30)
Employment status, n (%)			
Full or part time	9 (27)	0 (0)	9 (21)
Retired or home maker	19 (58)	9 (90)	28 (65)
Unable to work due to cancer or other disability	4 (12)	1 (10)	5 (12)
Missing	1 (3)	0 (0)	1 (2)
Marital status, n (%)			
Married/civil partnership/cohabiting	23 (70)	8 (80)	31 (72)
Separated/divorced	3 (9)	1 (10)	4 (9)
Widowed	3 (9)	1 (10)	4 (9)
Single	4 (12)	0 (0)	4 (9)
Diagnosis, n (%)			
NSCLC	30 (91)	6 (60)	36 (84)
SCLC	2 (6)	3 (30)	5 (11)
Pleural mesothelioma	1 (3)	1 (10)	2 (5)
Treatment received, n (%)			
Chemotherapy	16 (47)	4 (40)	20 (46)
Chemoimmunotherapy	10 (30)	5 (50)	15 (34)
Immunotherapy	1 (3)	1 (10)	2 (5)
Oral targeted treatments	6 (18)	0 (0)	6 (15)

[†], includes 2 who switched from Cohort 1 to 2. Cohort 1: patients with online access who completed weekly online symptom reports from home; Cohort 2: patients without online access who completed reports before each clinic visit with assistance. NSCLC, non-small cell lung cancer; SCLC, small cell lung cancer; SD, standard deviation.

eRAPID online symptom self-reports

Descriptive analysis of the type and severity of online symptom self-reports is presented in *Figure 6*, where the symptoms are grouped by the frequency of reporting (common symptoms occurring >50% of online completions, those reported 26–50% of completions, 10–25% and <10%). The most reported symptoms were fatigue (77%), problems with physical ability/performance status (76%),

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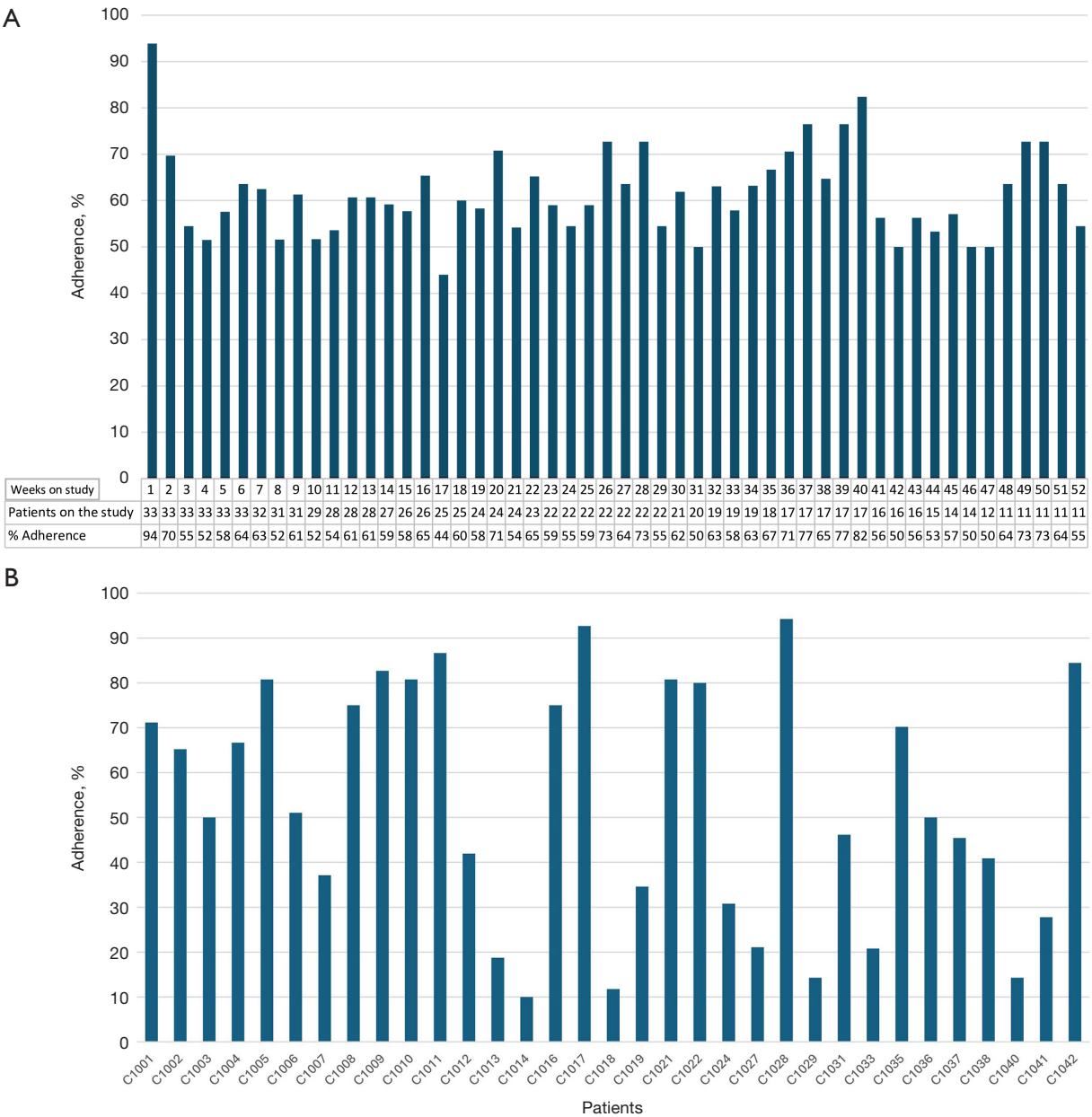


Figure 4 Cohort 1 patients (n=33): adherence to eRAPID online symptom reports. (A) Adherence to weekly eRAPID online symptom completions per protocol. (B) Individual patients' adherence to eRAPID online symptom completions. eRAPID, Electronic patient self-Reporting of Adverse events: Patient Information and aDvice.

pain (60%) and shortness of breath (59%). However, most patients reported predominantly mild symptoms. The added question on limb weakness or numbness (Yes/No answer) was reported by three patients on eight occasions (1% of symptom reports), and in one case, resulted in a diagnosis of brain metastases.

The clinical algorithm generated 56 notifications to the clinical team for severe symptoms (6.7%, 56/841) from 18 patients. The severe symptoms were physical limitations (n=13 times), rash (n=12), productive cough (n=9), weakness/numbness (n=8), pain (n=4), nausea (n=2) and shortness of breath (n=2), and once for lack of appetite, constipation, indigestion, itchy skin, vomiting, diarrhoea. Clinical staff responded to 45 notifications (fewer than 56,

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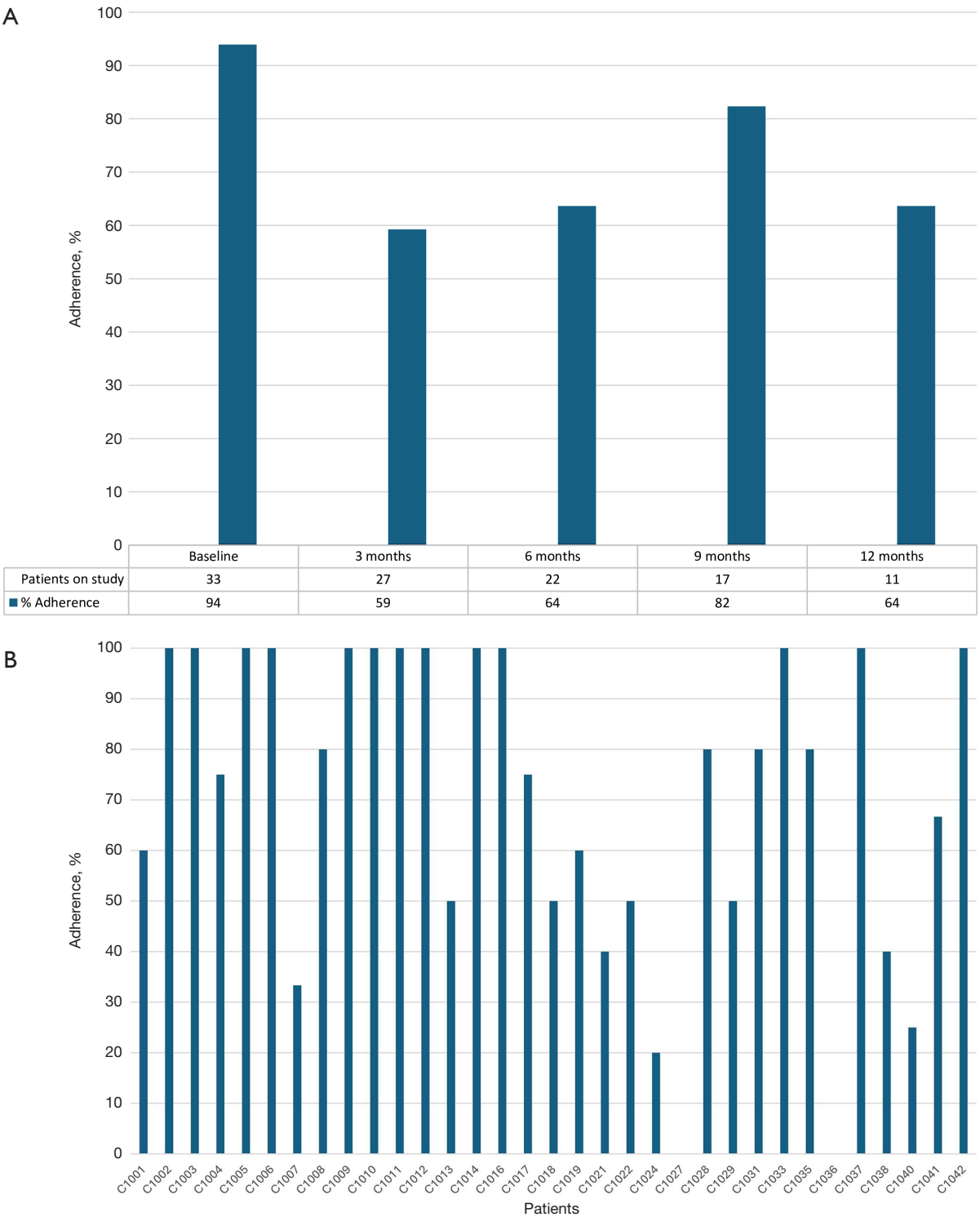


Figure 5 Cohort 1 patients (n=33): adherence to HRQoL questionnaires EORTC QLQ-C30 and EQ-5D-5L. (A) Adherence to quarterly quality-of-life completions per protocol. (B) Individual patients' adherence to quality-of-life completions. EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30; EQ-5D-5L, EuroQol 5-dimension questionnaire, 5 levels; eRAPID, Electronic patient self-Reporting of Adverse events: Patient Information and aDvice; HRQoL, health-related quality of life.

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Table 2 Cohort 2 patients (n=10): adherence to eRAPID symptom reports and HRQoL completions

No.	Weeks on study	Number of symptom report completions	Number of systemic treatment cycles	Adherence to online symptom reports (%)‡	Number of HRQoL completions (completed/expected)	Adherence to HRQoL completions (%)
1	50	7	4 (plus RT)	175	4/4	100
2	18	3	4 (plus RT)	75	2/2	100
3	52	10	10	100	5/5	100
4	15	4	3	133	1/2	50
5	52	15	16	94	5/5	100
6	51	11	13	85	5/5	100
7	27	3	4	75	2/3	67
8	4	1	1	100	1/1	100
9	52	11	9	122	3/5	60
10	52	8	10	80	4/5	80

‡, the number of expected completions was based on the number of systemic therapy cycles, so this resulted in three patients with adherence >100%. eRAPID, Electronic patient self-Reporting of Adverse events: Patient Information and aDvice; HRQoL, health-related quality of life; RT, radiotherapy.

excluding 11 multiple notifications generated when patients reported more than one severe symptom in a single online report requiring only one response by the CNS). 39/45 patients were called on the same or the next day (*Table 3*). There were 12 algorithm-related patient calls to the emergency hotline and six hospital admissions.

HRQoL data

The HRQoL questionnaire results over time are shown in *Figures 7,8*. Overall, patients self-reported relatively high scores (around 70 out of 100) on both measures (EORTC QLQ-C30 Global Health/Overall HRQoL Scale, the QLQ-C30 Summary Scores, and EQ-5D VAS, see *Figure 7*). The scores remained stable during the 12-month follow-up, which is likely due to the small sample and data not missing at random. Those patients whose disease progressed discontinued the study, and those who remained responded well to the treatment and felt better after completing the chemotherapy.

On EQ-5D, most patients had no, or only slight problems, with small numbers reporting moderate or severe issues, predominantly for Usual Activities, Pain and Anxiety/Depression (*Figure 8*). Fewer problems are reported at 9 and 12 months, as for the other scales.

Patient and healthcare staff perspectives of using eRAPID

Fourteen patients gave qualitative feedback: five male, nine female, mean age 67.3 years (range, 54–78). The patients received chemotherapy (n=6), chemoimmunotherapy (n=4), immunotherapy (n=1), or targeted therapy (n=3). Nine responses were obtained in the online survey, and six interviews were conducted (one female patient participated in an interview and provided an online response as well). Eight patients used eRAPID over 6 months (five online surveys and three interviews). The planned sample of 12 patients for interviews was not achieved due to COVID-19 restrictions.

Interim feedback at 4–6 months via the online survey was obtained from seven clinicians (n=3 CNS, n=4 consultants). Two end-of-study interviews were conducted (n=1 CNS, and n=1 consultant).

The framework analysis followed the pre-specified three interlinked themes with sub-themes, that were similar for patients and staff (*Table 4*). One emergent sub-theme was noted on the need for extra financial and management support to the team for sustainable implementation.

Theme 1. Ease and relevance of using eRAPID

Patients found eRAPID was easy to access and use, but

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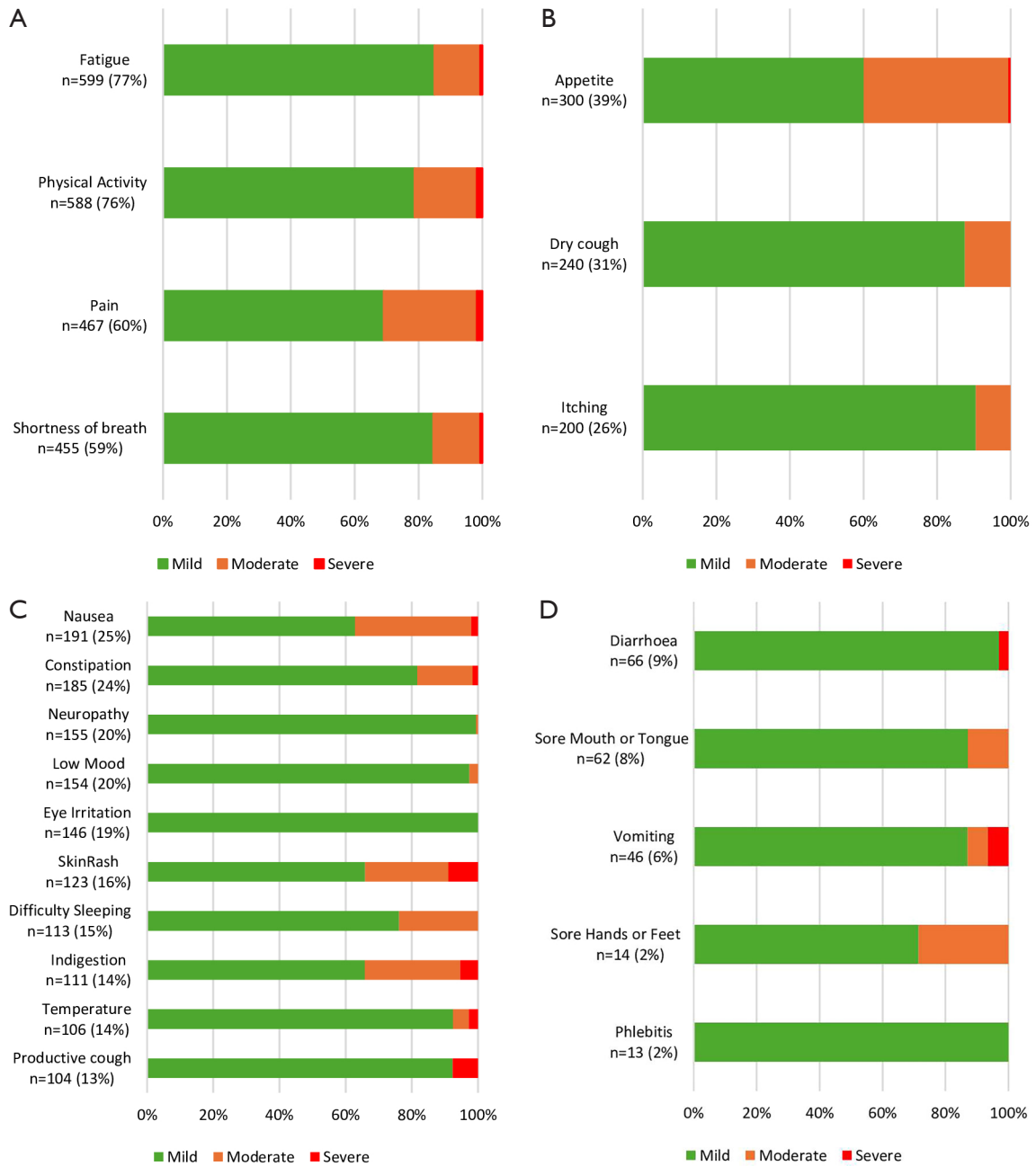


Figure 6 Type and severity of eRAPID online symptom reports. (A) Most commonly reported symptoms (>50% of reports). (B) Reported symptoms and severity levels (26–50%). (C) Reported symptoms and severity levels (10–25%). (D) Symptoms reported <10%. eRAPID, Electronic patient self-Reporting of Adverse events: Patient Information and aDvice.

feeling unwell after treatment could be a barrier for patients completing. The questionnaire was comprehensive but less relevant when patients felt well. Reporting frequency was acceptable, and reminders were helpful.

Staff reported that eRAPID was intuitive and comprehensive. The eRAPID reports within the patients' records were easy to access, and the graphs and tables were useful for trends and clarity.

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Table 3 Actions in response to eRAPID severe symptom notifications

Response	N
CNS contact following email notifications	
Contacted patient same day	24
Contacted patient next working day (out-of-hours completion =12)	15
Contacted patient within five working days	2
No contact	4
Total notifications	45
Notification actions	
CNS advised patient to contact bleep-holder at the hospital or contacted on behalf of patient	13
Patient contacted bleep-holder directly/at the hospital (not via CNS contact)	6
CNS informed/sought advice from consultant prior to next patient consultation	5
General advice given/other	17
No action	4
Total actions	45

CNS, clinical nurse specialist; eRAPID, Electronic patient self-Reporting of Adverse events: Patient Information and aDvice.

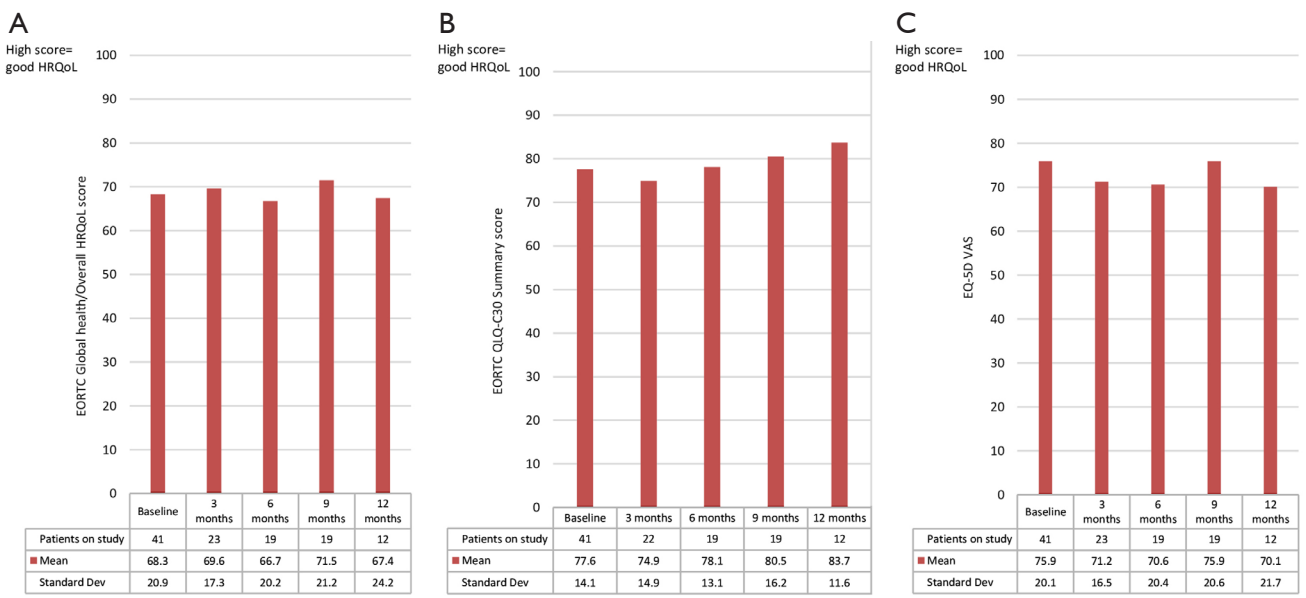


Figure 7 HRQoL data. (A) EORTC QLQ-C30 Global Health score. (B) EORTC QLQ-C30 Summary score. (C) EQ-5D VAS. EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30; EQ-5D VAS, EuroQol 5-dimension questionnaire visual analogue scale; HRQoL, health-related quality of life.

Theme 2. Impact on care and self-care

For patients, eRAPID helped them feel connected with the clinical team and provided reassurance. The validated self-management advice managed expectations regarding side effects and assisted patients in dealing with minor issues. Patients knew clinicians could access their reports. Some staff discussed reports during their visits, while other patients assumed staff awareness. Lack of discussion was

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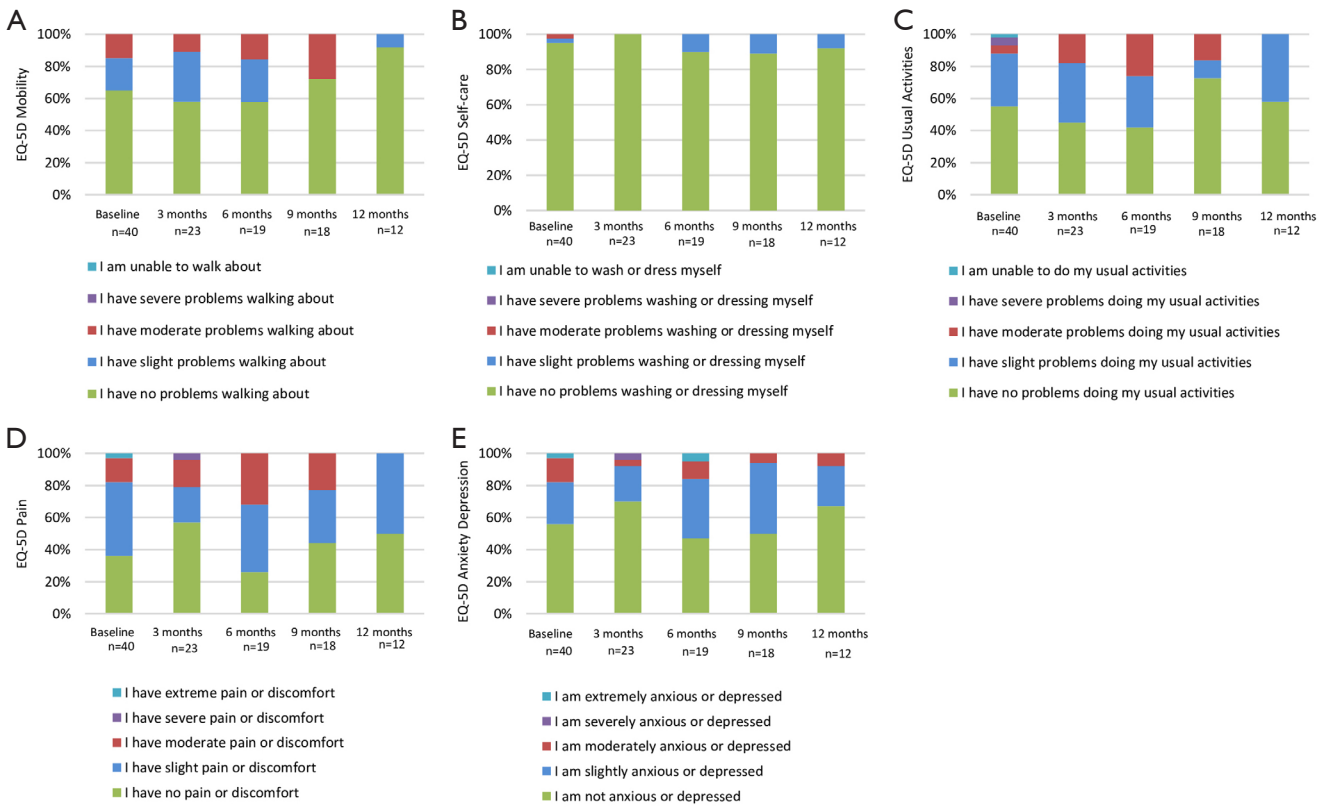


Figure 8 EQ-5D HRQoL data. (A) Mobility. (B) Self-care. (C) Usual Activities. (D) Pain. (E) Anxiety/Depression. EQ-5D, EuroQol 5-dimension questionnaire; HRQoL, health-related quality of life.

attributed to mild symptoms or time constraints and did not reduce patient adherence.

Clinicians perceived eRAPID as clinically valuable to guide and focus the consultations, leading to improved patient communication. It enabled proactive symptom management, and serious symptom notifications led to timely interventions.

Theme 3. Usefulness

Patients shared a view that eRAPID helped them track symptom patterns, functioned as a diary, and provided reassurance. Regular completions increased self-awareness and engagement. Some patients participated for altruistic reasons (supporting research and future patients). Patients endorsed eRAPID for routine care, with consent emphasised.

Staff reported several perceived patient benefits including increased autonomy, confidence and openness as well as reduced stigma and reassurance outside consultations. eRAPID was identified as an extremely valuable tool for connecting with this patient group, who are typically current or ex-smokers, and experience associated guilt with their diagnosis and disengage. eRAPID helped re-engage patients by offering an alternative method of disclosing symptoms. Staff perceived eRAPID to be a more anonymous, neutral way for patients to disclose symptoms at a time and place convenient to them. Patients were regarded as being more open online about their symptoms than in face-to-face appointments.

Overwhelmingly, clinicians felt eRAPID was useful in practice and endorsed its use in routine care, but they felt implementation was not possible without additional support, citing high workloads and staff shortages. Technology access could be a barrier for some patients.

Discussion

This real-world implementation study demonstrated that online symptom monitoring with ePROMs is feasible for about 50% of the eligible advanced lung cancer patients

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Table 4 Qualitative analysis themes and sub-themes

Themes	Patients		Clinicians	
	Sub-themes	Quotes	Sub-themes	Quotes
Ease and relevance of using eRAPID	Ease of use	• "*Simple to follow and access.*" (C1) • "*Easiest aspect was the multiple-choice options so not having to rank things myself. Better than describing in words the seriousness myself.*" (C1) • "*Found it harder reporting after treatment... feeling poorly.*" (C1)	Usable/intuitive	• "*No issues, able to contact patients and access the system.*" (CNS) • "*...very easy to use and simple to learn.*" (Oncologist)
	Relevance of symptom items	• "*Validated how I'm feeling. Questions are relevant.*" (C2)	Relevance of symptom items	• "*No clashes or differences in detail…worked well alongside other toxicity documentation*." (CNS)
	Reporting frequency	• "*A good weekly check on yourself to see if things are the same or have changed.*" (C1) • "*Happy with the frequency...timing relevant.*" (C2)	Data presentation	• "*...visual representation was clear and logical.*" (Oncologist) • "*(graphs) allowed for a quick overview of the symptom scores over time.*" (Oncologist)
Impact of eRAPID on care and self-care	Being connected to clinical team	• "*Helpful to have the phone number if you need to call them about symptoms.*" (C1) • "*Reassuring to know someone is there if needed.*" (C1) • "*Helpful to receive the red text with the information to contact the hospital...process was effective.*" (C1) • "*Received a call from the CNS around one or two days after...it was good to know that they were there to help.*" (C1)	Guided consultations	• "*Good to know the symptom reports before consultation.*" (Oncologist) • "*It is a good way of focusing consultations for patients on treatment.*" (Oncologist) • "*The symptom report was useful as identified issues for discussion.*" (Oncologist) • "*Any symptoms that were still of concern or showed an increasing trend in severity were discussed with the patient.*" (Oncologist) • "*…more time spent speaking to patients, sometimes other issues were highlighted and dealt with.*" (CNS)
	Management of symptom expectations	• "*If it's a mild thing, you can read the advice and try and manage and know whether it's a normal expected reaction.*" (C2)	Improved communication	• "*It enhanced contact with patient…it positively affected relations between nurse and patients.*" (CNS)
	Decision making aid on self-care	• "*The advice said if it gets any higher to contact the hospital. I then checked my temperature a few more times that week...probably wouldn't have checked regularly otherwise. It allowed me to keep on top of any side-effects.*" (C1) • "*Helps you clarify things, rather than just accepting.*" (C2) • "*Good reminder to contact hospital when you have certain symptoms.*" (C1)	Prompt for proactive early symptom management	• "*A couple of patients were struggling with daily activity, getting out of bed and fatigue via notifications… was able to support and refer to appropriate community services- Occupational therapy for aids and adaptations or district nurse.*" (CNS) • "*The notifications facilitated the ability to deal with symptoms in more timely fashion… if they needed admitting into hospital they were, or the issue was dealt with remotely.*" (Oncologist) • "*Useful tool for management of patient's symptoms/toxicity. The symptom report impacted on treatment management - pain, tiredness.*" (Oncologist)
Usefulness of eRAPID	Increased self-awareness and self-monitoring	• "*Makes me aware of symptoms for example I had a rash, and it encouraged me to keep an eye on it myself.*" (C1) • "*Identified pattern of symptoms.*" (C2) • "*I completed regularly to understand my symptoms and how it can be managed*" (C1) • "*It's like a diary. Once you get better, you don't remember. It's a good thing for you to look back on.*" (C2)	Patient benefits: autonomy, confidence, openness, reassurance	• "An excellent tool for patients to reassure and give them confidence when on treatment." (CNS) • "*They feel more confident reporting symptoms online…it gives patients some autonomy, they may feel more involved in their care and gives them control over what they report.*" (CNS)
	Reassurance	• "*Stopped me panicking and feeling I had to contact the hospital...gave me reassurance in the early days of treatment.*" (C2)	Anonymous symptom disclosure aids patient-clinician connections	• "*Useful, particularly for those patients who are less forthcoming with their symptoms and issues.*" (Oncologist) • "*Support the use of eRAPID within lung patients…they often don't engage with treatment due to the stigma of the disease e.g., they feel it's their fault for smoking and therefore withdraw themselves.*" (Oncologist)
	Considerations for implementation	• "*Worthwhile for others to do as might help them to open up and talk about things they struggle with*" (C2) • "*…should still be asked 'do I want to do this' rather than just being signed up.*" (C1)	Considerations for implementation	Potential barriers to electronic symptom reporting: • "*...lower socio-economic status and age of patients. Often less likely to engage with technology.*" (Oncologist) • "*Most patients could use IT or find someone who could support them…surprised at how IT savvy some people in their 80s and 90s were.*" (CNS) • "*Support roll-out. I feel this would be beneficial in supporting patients and clinical teams.*" (CNS) • "*Too much in the current climate e.g., too few nurses…needs to be supported at a Trust level as its management would be a full-time job e.g., adding patients, responding to notifications, engaging all patients.*" (Oncologist) If no online access: • "*...would be difficult for the clinical team to ring patients to do a completion over the phone in routine care.*" (CNS) • "*Could be improved with the use of static iPads within clinics for those without the required technology to do it from home.*" (Oncologist)

C1, Cohort 1 (patients with online access who completed weekly online symptom reports from home); C2, Cohort 2 (patients without online access who completed reports before each clinic visit with assistance); CNS, clinical nurse specialist; eRAPID, Electronic patient self-Reporting of Adverse events: Patient Information and aDvice.

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starting systemic treatment in a cancer centre. Participants' mean adherence to weekly reporting was 68% (50–70%) without a decline towards 12-months in the participants who remained on the study (11/33). These rates are comparable with other local studies but lower than the PRO-TECT trial in the USA (91%, 85–97%) (13,21,31). Age was not a barrier to ePROMs completion with both young and, more importantly, elderly cancer patients engaging (range, 36–82 years). Notably, the adherence to the added 3-monthly HRQoL questionnaires was also high, demonstrating that patients are willing to complete both. To the best of our knowledge, this is the first study to test combined frequent online reporting of symptoms to inform patient management, with standard outcome instruments of health and HRQoL. Such combined data is valuable for audit, evaluation of interventions and as part of real-world datasets.

The majority of clinical studies of online ePROMs report consent rates around 65–70%, whereas only 50% of all eligible patients accepted this study, despite offering in-clinic reporting to those not using the internet at home (32). In a real-world programme in 75 lung cancer patients, Girgis *et al.* reported a 61% participation rate (16). In addition, there was significant attrition rate with 65% of the patients leaving the study mainly due to disease progression, becoming too ill and moving to palliative care. We believe the lower recruitment and retention rates were partially related to the COVID-19 lockdown, which disrupted routine care. Lung cancer patients presented to the hospital later in their diagnosis as their symptoms were similar to those of COVID-19 infection (33). These figures also likely reflect the real-world nature of the study, screening and attempting to engage with all consecutive lung cancer patients. It is well known that this group of patients are often of poor functional status, high symptom burden, have many co-morbidities, and are socio-economically deprived.

The small number of participants who responded to their treatment remained on the study for the full 12 months and continued the regular symptom reports. This may suggest that symptom monitoring may be more clinically useful after successful first-line treatment. Available recent evidence showed that web-mediated follow-up of lung cancer patients without disease progression led to early relapse detection and improved survival (10).

To address the anticipated high digital exclusion in this patient population, the study design allowed in-clinic completion of online symptoms. Adding this option was supported by data from an RCT showing bigger benefit from ePROMs in advanced cancer patients without internet access, who completed ePROMs in clinics, in comparison with patients completing online from home (14). In our study, a quarter of the patients chose Cohort 2 with in-clinic completion. Unfortunately, due to COVID-19 lockdown, most of the consultations moved to telephone, with short hospital visits. Therefore, Cohort 2 ePROMs were predominantly completed over the phone with eRAPID researchers prior to clinical appointments, rather than the initial plan of completing on iPads in clinic. These patients may have been more reflective in their responses due to verbalising their answers in the researcher-patient dialogue. Alternatively, they may have felt less able to provide honest answers to a person than if they were completing alone on an iPad. They did not view or interact with the online system so were unable to offer anecdotal feedback on the design of eRAPID. The adherence to ePROMs in Cohort 2 was good, however this approach is too time consuming to be useful in routine practice. The number of patients in this implementation study was too small and diverse to make any meaningful comparisons between the cohorts.

The symptoms reported online were predominantly of mild or moderate severity, which seems somewhat counterintuitive considering the generally frail patient population, and this result differs from other studies (31). This likely indicated that patients who joined the study were relatively fit, with good performance status and suitable for systemic treatment. If they did not respond to the treatment and got progressively ill, they dropped out, and the patients who were doing well remained in the study. This selective drop-out is common in advanced cancer studies and explains why the HRQoL scores were, and remained, relatively high. One potential lesson from this study is to consider the patient population carefully for routine online monitoring, and perhaps choose a follow-up setting with stable patients, such as in Denis *et al.* (10). The eRAPID RCT in a diverse group of patients receiving chemotherapy for breast, ovarian and colorectal cancer also suggested the intervention benefited mostly patients with mild to moderate symptoms (13).

We have not analysed the online symptoms by treatment type due to the small number of patients. However, we provided a detailed analysis of the severe symptoms, generating notifications to staff and patient advice to contact the hospital. Of all symptom reports, 6.7% produced severe notifications, a higher proportion than our experience in breast, ovarian and colorectal cancer (at 1%) (13), and similar to patients on chemoradiotherapy for cancer of

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the cervix (21). This difference is likely due to the more symptomatic patients with advanced lung cancer and the use of different systemic treatments, especially immunotherapy. In advanced lung cancer, 33% of concerning symptoms were reported, but the thresholds for concerning severe symptoms are typically decided for each clinical setting and may have been different from this study (31). Staff receiving notifications did not believe this level to be burdensome or to increase their workload. The notifications prompted appropriate clinical actions, including hospital admissions and investigations.

The successes and challenges of regular symptom reporting and ePROMs in a real-world setting were examined. This design allowed the assessment of the utility to clinicians of ePROMs reporting and provided an opportunity to study customised patient interventions based on ePROMs reporting. Both patients and their clinical team accepted the eRAPID system to capture disease-related symptoms, treatment-related side-effects and HRQoL.

The qualitative work provided insights and explanations for the adherence findings and possible adaptations required to use eRAPID in routine practice. The results were consistent with previous in-depth qualitative studies in other cancers (30). Patients were content with regular symptom reporting, found it simple to use, and it was not deemed onerous. However, when they felt unwell after treatment, it was difficult to complete. This explains the high attrition rate with disease progression. Patients reported reassurance having access to validated information to aid decision-making about their own care. Participants described feelings of connectedness with their clinical team, despite doctors not always discussing symptom information in their consultations. This contrasts with other research that saw a reduction in patient adherence when clinicians did not use their data (13).

From the staff perspective, the eRAPID approach was feasible and useful. It was suggested that eRAPID data helped identify worsening conditions and thus enabled faster intervention. Although using symptom data did not necessarily save time in consultations, it was useful for identifying trajectories, focusing conversations, and building connections with patients. Of all lung patients the clinical team saw, a limited number were participating in eRAPID symptom reporting. Oncologists often forget to view and discuss the results. They asked for a clear label within an individual's EPR to highlight when patients were reporting online.

Although ownership, communication and engagement from the clinical team were excellent throughout the project, staff acknowledged they currently would not have resources to adopt the additional tasks required for eRAPID implementation (24). Such tasks included registration and recruitment of patients and assisting those with no internet access in completing symptom reports. Patient identification and recruitment worked well during the project as there was dedicated research support. Although the procedure can be condensed for routine care, it resembles a study so without continuous support, the registration process is too complex. Other successfully implemented research in routine care has had additional staffing and resources for these tasks (34). Dedicated support could include the appointment of a service manager and/or an ePROMs team in addition to the existing clinical champions (CNS and lead consultant) (24).

The project was conducted in a large tertiary cancer centre, screening all patients considered for systemic cancer treatment, which is a clear strength. However, several limitations should be acknowledged. The study recruitment started during the COVID-19 pandemic and lockdowns. The pandemic impacted the number of expected eligible patients, and recruitment was slower than expected. Patients presented to the hospital with more advanced cancer as their symptoms were similar to those of COVID-19 infection (33). Many patients were not suitable for systemic therapy due to poor performance status or experienced rapidly progressing disease. The high attrition rate in the study was likely due to this pandemic-related phenomenon. The planned number of patient interviews was not conducted due to social distancing rules. Useful feedback was gained via an online survey, but this did not allow the researchers to probe and explore answers further. The interview sample of patients was slightly skewed towards those who did engage with eRAPID, but this was offset by including patients who intermittently completed to ascertain reasons for non-compliance. Both cohorts were interviewed and patients at different time points of eRAPID use were included, providing a breadth of feedback and engagement at different stages. Longitudinal feedback from individuals may give a better indication of a person's engagement with eRAPID over time.

Conclusions

The use of ePROMs in current practice is becoming more commonplace, so the lessons from this project will inform future NHS implementation. Choosing the patient population and treatment setting is important to maximise

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the benefits for patients and services. Ongoing training and involvement with clinical staff are vital to promote the use and value of ePROMs. Dedicated central IT support for ePROMs, ideally as part of the existing EPR systems, will facilitate patient registration and engagement. Investment from NHS stakeholders for these necessary resources is essential to ensure implementation is viable in the future. These lessons learned are being taken forward in the implementation of eRAPID in routine care when working towards sustainable business support for establishing digital clinics. Despite administrative, financial and IT barriers to routine collection of symptom reporting using ePROMs in cancer settings, continued exploration of systems in practice is fundamental.

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Footnote

Reporting Checklist: The authors have completed the SQUIRE reporting checklist. Available at https://jtd.amegroups.com/article/view/10.21037/jtd-2026-0602/rc

Data Sharing Statement: Available at https://jtd.amegroups.com/article/view/10.21037/jtd-2026-0602/dss

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki and its subsequent amendments. The study was approved by East Midlands-Leicester South Research Ethics Committee (20/EM/0026, 5th March 2020) and informed consent was obtained from all individual participants.

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