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Research article

# The use of volunteers to implement electronic patient reported outcomes in lung cancer outpatient clinics

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ABSTRACT

*Background:* Treatment related toxicity is common after chemotherapy and radiotherapy. Our group has developed and validated an electronic Patient Reported Outcome questionnaire (ePRO) to assess symptoms and toxicity in lung cancer patients receiving (chemo)radiotherapy treatment. We assessed the need for volunteer support in clinics to assist patients in completing ePROs.

*Methods:* Lung Cancer patients attending outpatient or radiotherapy clinics at The Christie NHS Foundation Trust, Manchester were consented and asked to complete a Patient Reported Outcomes questionnaire using an electronic device (a touchscreen). Trained volunteers were available if patients required help such as verbal or physical assistance. The primary objective was to determine the need for volunteers to assist lung cancer patients in completing ePROs.

*Results:* 27/86 (31.4%) of patients who consented to this study required assistance to complete the ePRO. After questioning, we found that only 7/86 (8.1%) would have relied on volunteers for assistance as the majority of patients had a companion that could have provided help. 81/86 (94.2%) of patients were satisfied with the use of a touchscreen tablet to complete the ePRO.

*Conclusion:* Our results demonstrate that the introduction of ePROs in lung cancer outpatient clinics is feasible, even without the use of volunteers for the majority of patients. The implementation of ePROs would allow large volumes of high quality (chemo)radiotherapy toxicity data to be collected accurately and quickly. This is essential for the development of predictive models of outcome using population-based data, which could allow the personalisation of (chemo)radiotherapy treatment for lung cancer patients.



## Introduction

Chemotherapy and radiotherapy play a major role in the treatment of lung cancer patients. Treatment-related toxicity is common in patients treated with radiotherapy with or without chemotherapy ((chemo)radiotherapy) [1,2]. The standard for grading treatment-related toxicity in the context of clinical trials is clinician-led, using the Common Toxicity Criteria for Adverse Events (CTCAE) [3]. In the routine setting toxicity data is generally not recorded in a structured or consistent way and data is often missing, possibly due to time constraints during busy oncology clinics. The use of Patient Reported Outcome questionnaires (PROs) is a solution to collect such data in a more efficient manner. PROs have been shown to be more accurate, highlight more symptoms, and provide more details than traditional clinician-based reporting. It has been demonstrated that clinician graded toxicity tends to underestimate symptom severity, and is influenced by patient-clinician dynamics and inter-rater variability [4]. PRO data collection eliminate these factors by allowing patients to prospectively describe and grade their own symptoms using a validated questionnaire derived from the CTCAE system [5,6]. Recent randomised controlled trials have shown that cancer patients followed up with the help of PRO tools have a significantly better survival compared to patients followed up in a standard way [4]. These trials highlight the importance of the introduction of such tools in the clinic.

*Abbreviations:* ePRO, Electronic Patient Reported Outcome; CTCAE, Common Toxicity Criteria for Adverse Events; IMD, Index of Multiple Deprivation; ACE, Adult Comorbidity Evaluation.

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Electronic data collection has many practical advantages over paper-based PROs including ease of data collection and storage. It also allows more efficient data analysis without compromising data validity [7,8]. This platform could allow large volumes of high-quality large scale prospective toxicity data to be gathered for the development of predictive toxicity models following treatment for lung cancer with (chemo)radiotherapy [9]. Treatment decisions are often based on clinical trials that involve younger, fitter individuals without comorbidities. Given that the median age of patient diagnosed with lung cancer is 70 years [10], elderly patients would benefit from individualised treatment based on the use of predictive models.

Previous literature shows that the use of ePROs in cancer outpatient consultations is feasible and acceptable to patients [7,11,12]. There is currently very little data to understand the feasibility of implementing ePROs in the lung cancer population. This group of patients are generally elderly and come from lower socioeconomic backgrounds [13]. The primary aim of this study was to understand if volunteers were necessary to implement ePROs in lung cancer patients. Further aims were to identify which particular patient groups are more likely to require assistance and if help is given whether this has an impact on completion rate at subsequent visits. We also aimed to understand patients' satisfaction with the introduction of ePROs.

## Materials and methods

### *Patients*

This study recruited patients between May and July 2016 at a large UK cancer centre. Eligible patients were aged 18 and over with a histological or clinical diagnosis of lung cancer, attending lung cancer or radiotherapy treatment clinics at The Christie NHS Foundation Trust. Patients unable to give informed consent, attending lung cancer clinics for the first time, or had previously completed ePROs were excluded from the study. The study protocol gained ethical approval by the North of Scotland Research Ethics Committee.

### *Study design*

This was a prospective open questionnaire based study. Enrolled patients were asked to complete three questionnaires consecutively during a single hospital visit (as shown in Fig. 1) and if possible were asked to complete the questionnaires again at a subsequent visit.

Two of the questionnaires (Q1&3) were completed on paper and one electronically (Q2). Questionnaire (Q1) (see Appendix A) collected patient demographic information. A patient satisfaction questionnaire (Q3) (see Appendix B) was also completed on paper before and after completion of the ePRO questionnaire and provided feedback regarding the use of ePROs. The rationale for using paper for Q1&3 was to encourage participation in patients hesitant towards using electronic devices.

The ePRO questionnaire (Q2) (see Appendix C) was completed on a web tool using a touchscreen tablet that was cleaned between uses. It was an electronic adaptation of a previously validated paper PRO used to collect data on acute toxicities and performance status (PS) for lung cancer patients receiving (chemo)radiotherapy [14]. During our study, completed ePROs were uploaded to The Christie's electronic patient record to allow doctors to access them in real-time before the consultations.

Patients who consented to the study completed the three questionnaires at up to two time points. The first time-point was at baseline (the first clinical visit) and the second at their subsequent clinic visit if this was possible during the timeframe of the study. All data was collected over a 6-week period.

Patients were given no training on using touchscreen devices before being asked to complete the ePRO questionnaire. Patients received the tablet with a new ePRO form ready to complete. They were asked to attempt to complete ePRO unaided if possible. If help was required, the volunteer/researcher was available to provide assistance. This included both verbal and physical help in order to complete ePRO using the touchscreen tablet. The key reason we asked companions not to assist was because we wanted to find out what proportion of patients required help completing an ePRO. We recorded the main difficulties patients encountered when using the touchscreen tablet to complete ePRO. The study also investigated if a companion attending clinic with the patient could have helped with ePRO completion to determine volunteer necessity. The volunteers were recruited using The Christie NHS Foundation Trust regulated and vetted volunteer service, and had received training regarding ePROs and the study process.

There are a number of challenges associated with creating a platform to collect ePRO securely within a hospital's electronic record. It is essential that volunteers and patients did not have access to other patients' confidential information. For eligible patients attending clinic, a link to a web address was created that would open a new ePRO form within the patient's record. These links were verified by the research student and stored on a web page only accessible by the research student. Each patient's link was identifiable by their clinic date, time, and their hospital number. A trained volunteer or research student would open the link on the patient's behalf, before asking the patient to complete ePRO. Access to any other webpages during or after completion of the ePRO questionnaire was denied by design, preventing inadvertent access other patients' electronic record.

Patients' clinical data regarding disease and treatment were obtained from the patient electronic record. Patients' postcodes were also extracted to calculate an Index of Multiple Deprivation (IMD). Areas in the UK are ranked from 1 (most deprived) to 32,844 (least deprived), with each area representing a small piece of the country containing an average of 1500 people. The calculation is based on seven domains such as income, employment, and health, each given different a weighting [15].

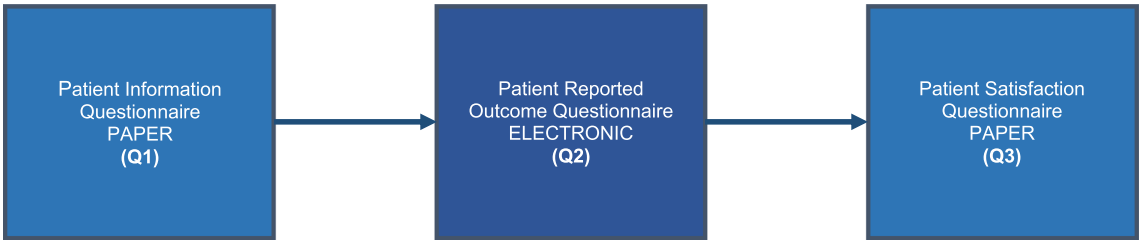


**Fig. 1.** Questionnaires used in the study, completed in the order shown.