

C.P. has received consultancy fees for Astra Zeneca and Medela. J.F. received an honorarium for providing a patient perspective from BluePrint Medicine, Novartis, Janssen, Takeda, EQRx, and AstraZeneca.

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## THE VALUE OF PATIENT-REPORTED OUTCOMES IN LUNG CANCER CLINICAL TRIALS



### TRIALS

#### To the Editor:

We carefully read the interesting article by Heiden and colleagues<sup>1</sup> assessing patient-reported pain, dyspnea, and functional status up to 1 year after lung resection. We congratulate the authors for their efforts in collecting patient symptoms through the National Institutes of Health–developed Patient-Reported Outcomes Measurement Information System 4 times after lung cancer resection.

Although minimally invasive techniques and perioperative enhanced recovery plans have improved the experience of care, all treatments may have a devastating effect on patients' lives, with longitudinal data demonstrating a similar pattern up to 1 year in the United States as in Europe.<sup>2</sup> We are concerned that measures of clinical effectiveness cannot capture a patient's treatment goals or how they feel and are functioning. Tolerable is more than managing side effects; it is being able to function. The patient perspective on symptoms, side effects, the severity of them, and how they impact a person's life is critical when looking at risk versus benefit of treatment.

To better understand toxicity in the context of rapid advances in treatments, we need a more granular patient-reported outcomes (PROs) collection and various time points and with possible different symptoms-specific combinations. The Patient-Reported Outcomes Measurement Information System and the new European Organisation for Research and Treatment of Cancer Lung Cancer module<sup>3</sup> offer a more dynamic pattern that reflects the new approach to lung cancer multimodality treatments.

Effects do change through the course of treatment, especially compounded with each line of treatment. Therefore, we believe longitudinal follow-up is essential.

Preferences and goals are unique to each patient and vary depending on age, lifestyle, occupation, type of treatment, etc. An individual's ability to cope with the direct effects of treatment has a direct impact on adherence, stress, and quality of life—which all affect outcomes. For PROs to be useful, they must capture a patient's total experience, including both acute and late-onset side effects that are being missed. There are a lot of data on acute effects. However, patients are living longer, and there is not much, if anything, on late, rare, long-term effects that affect quality of life (physical, psychosocial, and financial especially). PROs should be flexible to this change and must be able to be integrated into clinical records. The technology will be able to help in this as more and more patients with lung cancer will have access to smartphones and new devices.

The future of treating lung cancer is a multimodality, personalized approach with the “expectation” that patients will live a long time. Safety and effectiveness are the end points for trials, not quality of life. We must use PROs, and they must be patient-important outcomes, and for this reason, patients should be involved in developing research and clinical guidelines from the beginning. Overall survival is not the only important end point to patients. Patients and families value moments and milestones and want hope; hope to live long enough and well enough to reach and enjoy the next milestone.

We have missed an opportunity to collect meaningful data that could provide valuable insight on hurdles and/or opportunities that could help stratify patients to the best treatment and mitigate side effects. In this rapidly evolving treatment landscape, the patient perspective is necessary to bridge that gap between what can be done and what the patients want. PRO measurements need to be relevant; it is essential to ask the right questions in the right way at the right time.

Cecilia Pompili, MD, PhD<sup>a,b</sup>

Jill Feldman<sup>c</sup>

<sup>a</sup>Section of Patient Centred Outcomes Research  
Leeds Institute for Medical Research  
St James's, University of Leeds

Leeds, United Kingdom

<sup>b</sup>Thoracic Surgery Unit

University Hospital

Verona, Italy

<sup>c</sup>EGFR Resisters

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