



Good Practice from the Patient's Perspective

"A great step forward. A good document that hits all the right spots"

Professor Sanjay Popat
Consultant Thoracic Medical Oncologist, The Royal Marsden Hospital

"This is an excellent document"

Dr Riyaz Shah
Consultant Medical Oncologist, Kent Oncology Centre

"Another great initiative! I am fully supportive of this excellent document and we will happily disseminate it to our patients"

Dr Fabio Gomes
Consultant Medical Oncologist, The Christie NHS Foundation Trust Manchester



Introduction

The purpose of this document is to empower patients to be involved in and informed about their treatment.

It is intended for use by patients diagnosed with EGFR mutation positive Non-Small Cell Lung Cancer (NSCLC), the majority of whom will have been diagnosed at Stage 4.

We have drawn heavily on the European Cancer Organisation's Code of Cancer Practice. Views expressed in the document are those of the charity and reflect the good practice that our members have experienced at the hands of leading thoracic medical oncologists.

Information

You have the right to information about your disease and treatment from your medical team and other resources, including patient and professional organisations.

Key questions you may wish to ask

- ▶ Will I be able to decide how much information I should receive about my diagnosis, treatment (including benefits and risks) and the management of my disease?
- ▶ Can I bring a relative or friend to my consultations?
- ▶ Will my available treatment options be explained to me?
- ▶ Will I receive written information about my cancer, and will I be given contact details for relevant patient-supporting organisations?

Shared Decision-making

You have the right to participate in shared decision-making with your healthcare team about all aspects of your treatment and care.

Key questions you may wish to ask

- ▶ Can I discuss the approach that we will take in making decisions about my care and agree how my voice is heard?
- ▶ Can we share decision-making so that I feel empowered and involved in deciding my treatment options?
- ▶ Does the cancer service encourage patient engagement, involvement and empowerment?

Research and Innovation

You have the right to be informed about ongoing research relevant to your cancer including your eligibility to participate in research.

Key questions you may wish to ask

- ▶ Is this cancer service active in cancer research, enrolling patients in clinical trials and supporting innovation?
- ▶ Is there a study or clinical trial in which I could participate if I am eligible and I choose to do so?
- ▶ Can I go to another hospital or centre if I wish to be involved in a specific clinical research project not offered at this hospital?

Quality of Life

You have the right to discuss with your healthcare team your priorities and preferences to achieve the best possible quality of life.

Key questions you may wish to ask

- ▶ During my treatment, how will I be able to maintain the optimum quality of life so that I can live as normal a life as possible?
- ▶ Will this cancer service measure the quality of my life in any way, such as using Patient Reported Outcome Measures (PROMs)?
- ▶ Will this cancer service actively consider whether I have emotional, social, or financial problems relating to my diagnosis or treatment?

Quality, Expertise and Outcomes

EGFR mutation positive lung cancer comprises about 10-15% of lung adenocarcinoma. Not all oncologists will be experienced in treating EGFR+ patients.

It is the view of the charity that all EGFR+ patients should have the opportunity of being treated at a centre of excellence by a thoracic medical oncologist experienced in EGFR mutation positive lung cancer.

Key questions you may wish to ask

- ▶ Will my diagnosis and treatment be managed by a team of healthcare professionals with the necessary expertise to give the best advice and identify the best available options for me?
- ▶ What experience does my healthcare team have in treating EGFR+ patients?
- ▶ How many new EGFR mutation positive patients do you see every year?

- ▶ Do I have the right to ask for a second opinion?
- ▶ If I wish, can I be referred to a centre of excellence where I can be treated by oncologists who have more experience in managing EGFR positive lung cancer?

Scans

It is important that scans are regularly carried out to ascertain whether your cancer has progressed. It is the view of the charity that a computerised tomography (CT) scan of both thorax and abdomen should be carried out every three months.

Key question you may wish to ask

- ▶ How often will I receive a CT scan?

Spread to the brain (brain metastasis) is common in EGFR+ lung cancer. It is the view of the charity that patients should receive brain magnetic resonance imaging (MRI) at diagnosis and at not more than six monthly intervals (even if asymptomatic) and, if brain metastases are found, not more than every three months. (If brain metastases are found patients will no longer be able to drive).

Key question you may wish to ask

- ▶ How often will I receive a brain MRI?

It is important that you are notified of the result of your scans quickly.

Key questions you may wish to ask

- ▶ How long after a scan will I be informed of the result?
- ▶ How will I receive this information?
- ▶ If brain metastases are found will my case be discussed at a neuro-oncology MDM with access to neurosurgery and SRS?

NSCLC can also spread to the bones.

Key question you may wish to ask

- ▶ If cancer is found in the bones, will I receive bone-strengthening medication such as denosumab?

Side Effects

Treatments for EGFR+ lung cancer can have significant side effects and it is important that you can discuss these and any other matters about your treatment between meetings with your consultant. It is the view of the charity that each treatment centre should have a Lung Cancer Nurse Specialist who you can contact at short notice.

Key questions you may wish to ask

- ▶ What side effects might I experience?
- ▶ Who should I tell if I suffer severe side effects?
- ▶ Do you have a Lung Cancer Nurse Specialist that I can contact at any time?
- ▶ If the LCNS is not available, how do I leave a message and will I be called back quickly?
- ▶ If the treatment centre doesn't have a LCNS, who can I contact between consultations if I have any concerns?

Progression

Patients diagnosed at stage 4 are usually treated with a tyrosine kinase inhibitor (TKI). Whilst this treatment can be extremely effective in delaying the development of the cancer, it is likely that, at some point, the cancer will progress.

Key question you may wish to ask if progression occurs

- ▶ What tests will be carried out, including biopsies, to ascertain the most effective next line of treatment?
- ▶ Will biopsies, either tissue or liquid, utilise Next Generation Sequencing in order to identify whether I have any other targetable mutations?
- ▶ What clinical trials are suitable for me?
- ▶ Are there any drugs available on compassionate use/named patient use from industry that may be suitable for me?"
- ▶ If appropriate, will I be referred to a team experienced in oligo progressive disease?
- ▶ If appropriate, will I be referred to a neuro-oncology team experienced in the care of EGFR+ brain disease?

Integrated Palliative and Supportive Care

You have the right to receive optimal supportive and palliative care during any part of your cancer journey. This might include help in managing physical symptoms such as pain and also may include emotional, spiritual and psychological support.

Key questions you may wish to ask

- ▶ Should it be necessary, will I be given supportive and palliative care based on my individual needs?
- ▶ Can I ask to be referred to the supportive and palliative care service at any time?
- ▶ Is the supportive and palliative care service provided at home or in hospital?

Further Information

This information has been put together by the EGFR Positive UK charity which is run by patients, their families, and friends. If you have any questions about EGFR mutation positive lung cancer, or to join our online community, contact us at contact@egfrpositive.org.uk

To find out more about the charity visit www.egfrpositive.org.uk

Please remember, you are not alone, and support is always available.