Original article

ALK Positive Lung Cancer (UK)

ALK-positive NSCLC: Frequency of Routine Head Magnetic Resonance Imaging (MRI): Need for UK Protocol.

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Brainstrust - the brain cancer people - is proud to endorse this paper.

A diagnosis of brain metastases can be overwhelming, but implementing a regular scanning interval protocol can help ease the psychological burden. It also facilitates earlier treatment, reduces reliance on long-term steroids, and helps prevent the severe symptoms often associated with brain metastases.

Dr Helen Bulbeck
Director of services and policy
brainstrust - the brain cancer people

If you have ALK-positive lung cancer and are not receiving brain MRIs in accordance with the Protocol at para 5.0, you may wish to share this booklet with your doctor or other healthcare professional.

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ALK Positive Lung Cancer UK

A registered charity in England and Wales, registration number 1181171. A registered charity in Scotland, registration number SC053692.

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1.0 Introduction

1.1 ALK-positive NSCLC is caused by the rearrangement of the anaplastic lymphoma kinase (ALK) gene with another gene, inducing tumour growth. About 78% of patients are never smokers and about half are under the age of 51 years at diagnosis.[1] About 61% of patients are diagnosed at stage IV,[1] when there is no cure but modern targeted therapy may extend the life of some patients, sometimes for many years.[2]

1.2 ALK Positive Lung Cancer (UK) is a charity registered in England and Scotland. Its aims are to support and empower patients with ALK-positive lung cancer; to advocate for best practice throughout the UK; and to raise awareness of lung cancer (LC) in never-smokers.

1.3 ALK-positive NSCLC patients are more likely to develop brain metastases than other lung cancer patients,[3] with about 26% having brain metastases at diagnosis.[4]

1.4 Current 2nd generation Tyrosine Kinase Inhibitors (TKIs), Alectinib and Brigatinib, are effective in controlling brain metastases for many patients but a further 34% are likely to develop brain metastases within 3 years of diagnosis.[4]

1.5 Early identification of brain metastases is important so that stereotactic radiotherapy (SRS) treatment can be explored. SRS is highly-focused, high dose radiotherapy suitable for a small number of brain metastases only. Treating brain metastases in a timely fashion is important to prevent difficult and impactful symptoms such as impaired thinking, limb weakness and seizures, and may well help reduce the need for long-term steroids.

1.6 In contrast, delayed identification of brain metastases, including waiting for patients to exhibit symptoms, may potentially mean greater numbers and larger brain metastases preventing SRS or increasing the risk of SRS complications.[5]

1.7 The alternative form of radiotherapy, whole brain radiotherapy, is inferior to SRS as brain metastases are controlled for a shorter time and it is associated with more side effects.[6]

1.8 MRI is the most effective way of identifying brain metastases as CT scans have limited sensitivity for detecting small brain metastases which are usually suitable for SRS.[6]

2.0 Patient Data

2.1 A survey of patients published in 2022 by the ALK Positive Lung Cancer (UK) Charity indicated a wide variation in the frequency at which head MRI is carried out in UK cancer centres.[7]

2.2 58 patients responded to a survey conducted by the Charity in March 2025, as follows -

Frequency of Regular Head MRI

Intracranial Control	Never *	3-monthly	6-monthly	12-monthly	other
With brain metastases (n=15)	-	15 (100%)	-	-	-
Without brain metastases (n=43)	18 (42%)	1 (2%)	14(33%)	7 (16%)	1 x 8 months 2 x 6 months CT

* Some patients report that they will receive a head MRI if they exhibit symptoms.

2.3 Patients are aware that finding brain metastases may, but not always, require them to surrender their driving licences.[8] It is for the patient, in consultation with the doctor, to decide whether to forego regular routine surveillance head MRIs for this reason.

2.4 Patients talk to each other and cannot understand that there is not an agreed national protocol for the frequency of head MRI in those affected by ALK-positive NSCLC.

3.0 Guidelines

3.1 There are no approved national guidelines in the UK or internationally concerning the frequency of head MRI for ALK-positive LC patients.

3.2 The National Institute for Health and Care Excellence (NICE) issues guidance on management of brain metastases which allows follow up of patients with head MRI, according to their risk.[9]

3.3 The European Society for Medical Oncology (ESMO) provides guidelines for the management of brain metastases, including the frequency of scans.[10]

3.4 Many UK oncologists follow the ESMO guidelines but more commonly individual health trusts have developed their own local protocols which often do not account for specific subgroups of patients with a greater preponderance for brain metastases, such as those with ALK alterations, which are more associated with brain metastases.

4.0 Best Practice in the UK

4.1 The Charity has considered

- the guidelines produced by NICE and ESMO
- the protocols in use at UK centres where large number of ALK-positive patients are treated
- the views of UK leading thoracic oncologists.

5.0 National Protocol

The Charity recommends that the protocol below be adopted by all Hospital Trusts in the UK as best practice for the frequency of head MRI of ALK-positive NSCLC patients.

This Best Practice statement is based on the efficacy of 2nd generation Alectinib and Brigatinib. It will be reviewed if 3rd generation TKIs, e.g. Lorlatinib, become available for first line use in England and Wales.

Situation	Frequency of Head MRI
At diagnosis of ALK-positive NSCLC	All patients to receive head MRI to establish the presence of brain metastases and a baseline for future comparison.
If no brain metastases are found at diagnosis	6-monthly scans
Brain metastases present at diagnosis or Brain metastases develop during treatment	3-monthly scans. Scans can reduce to 4 or 6-monthly if either complete response (disappearance of lesion) or durable partial response (minimal residual abnormality that is stable) over a prolonged period at least 12 months.

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Acknowledgements for their advice in the preparation of this report: Professor S Popat (The Royal Marsden Hospital, London), Dr J Evans (Imperial College Hospital, London), Dr J Heseltine (Clatterbridge Cancer Centre, Liverpool) and Dr G Walls (Queen's University, Belfast).

This booklet has been produced by

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A registered charity in England and Wales, registration number 1181171. A registered charity in Scotland, registration number SC053692.

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Version 1. Published: May 2025. Next review date May 2027.