

ORIGINAL RESEARCH

The Need for a National Guideline for the Management of NSCLC ALK-Positive Lung Cancer in the UK: Results of Patient-Driven Surveys

DEBRA MONTAGUE

ALK Positive Lung Cancer (UK)

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Support • Empower • Advocate

Introducing ALK Positive Lung Cancer (UK) – a vibrant, active and determined community dedicated to helping every person diagnosed with this rare, currently incurable, cancer to receive the best care possible and live their best life for as long as possible.

The charity has one fundamental goal: to extend the overall survival and quality of life of ALK-positive lung cancer patients across the UK. ALK Positive Lung Cancer (UK) was established in 2018 by patients, their families and friends. Our journey began as a social media patient support group, and we have grown to become a well-respected and trusted source of ALK-positive lung cancer information. We are recognised by the National Institute for Health and Care Excellence (NICE) as an organisation to be consulted on new ALK-positive treatments.

Today, ALK Positive Lung Cancer (UK) provides an invaluable platform where patients and their families can exchange information about their diagnoses and treatments, and give and receive mutual support.

The charity is a primary source of information to inform and empower patients about their disease, available treatments and best-practice disease management.

We advocate on behalf of ALK-positive patients to ensure that they receive the highest level of care, whatever their demographic and wherever they live in the UK.

The Need for a National Guideline for the Management of NSCLC ALK-Positive Lung Cancer in the UK: Results of Patient-Driven Surveys

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There are currently no national guidelines specifically for the management of NSCLC ALK-positive lung cancer in the UK. National guidelines exist for lung cancer in general and reference is made to ALK-positive lung cancer. However, the generic nature of these guidelines is not sufficient for the optimal management of this specific type of lung cancer, with its unique disease management requirements.

Method: In 2021, members of the charity ALK POSITIVE LUNG CANCER (UK) completed anonymised surveys to gather real-world data about their treatment. **Results:** Data were gathered on the prescribing of blood thinners (n = 127); frequency of brain MRI scans (n = 123); prescribing bone strengthening medication (n = 127); frequency of CT scans (n = 123); mental health (n = 132). There was significant variation in each of these five aspects of treatment. **Conclusions:** The findings, from a representative population of ALK-positive patients, provide new information on the significant disparities in the treatment that patients receive. This health inequality is likely to have a detrimental effect on the survival outcomes for some of these patients. It would improve patient outcomes and overall survival if ALK-positive lung cancer disease management national guidelines were established and utilised across the NHS in the UK.

1. INTRODUCTION

Lung cancer is the third most common cancer in the UK, and the biggest cause of cancer-related deaths. Every year, around 48,500 new lung cancer cases are diagnosed in the UK, of which about 2000 are confirmed as ALK-positive lung cancer [1]. Lung cancer outcomes in the UK are amongst the worst in developed nations [2]. Lung cancer in never-smokers is now the UK's 8th most common cause of cancer-related death, causing nearly 6000 deaths a year [3].

ALK-positive lung cancer is a rare type of non-small cell lung cancer (NSCLC) in which the cancer cells have a mutation in the anaplastic lymphoma kinase (ALK) gene. The mutation is a gene rearrangement: usually, an abnormal fusion of ALK and echinoderm microtubule-associated protein-like 4 (EML4). The ALK rearrangement is present in approximately 5% percent of people with NSCLC [4].

To meet the needs of patients with non-small cell lung cancer (NSCLC) with an oncogene-driver, patients have organised into support groups. These groups are building partnerships to provide support and education and to help patients access treatment through sharing information and promoting advocacy.

ALK Positive Lung Cancer (UK) is a registered charity established by patients of ALK-positive lung cancer and their families. Founded in 2018, the charity's aims are to provide support, empowerment and advocacy for patients so as to improve quality of life and overall outcomes.

The charity leverages the power of its community of patients to carry out independent research to support change in the healthcare system. As part of its development strategy, ALK Positive Lung Cancer (UK) is seeking to establish national guidelines for the management of ALK-positive lung cancer in the UK.

National guidelines would improve outcomes for patients by ensuring that the most effective tests and treatments are used, as well as ensuring that patients have access to suitable palliative care, follow-up, and support. National guidelines exist [5] for lung cancer in general, with reference to NSCLCs (such as ALK-positive lung cancer). However, the generic nature of these guidelines is not sufficient for the optimal management of this specific type of lung cancer, with its unique disease management requirements, in order to consistently deliver best possible outcomes for every patient.

This paper will illustrate the variations in five aspects in the management of ALK-positive lung cancer in the UK, building to the conclusion that a national guideline is imperative to improve quality of life, care, and outcomes for UK patients.

2. METHOD

Data were gathered through anonymous membership surveys conducted in 2020 and 2021. The surveys were made available to all members via Facebook, since this is the primary communications platform for members of the charity. This is a closed platform for patients and carers. The surveys were generated by SurveyMonkey.com.

3. RESULTS

3.1. Blood Clots & Blood Thinning Medication (n = 127)

Cancer can increase the risk of developing blood clots [5] which are potentially fatal if left untreated. Certain cancers, such as lung cancer, are known to be more associated with the increased risk of blood clots. Blood stickiness, certain treatments and reduced activity are all potential causes of increased blood clots in cancer patients.

What percentage of patients have developed a blood clot since diagnosis?

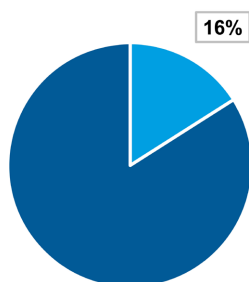


Figure 1. Frequency of blood clots

A recent survey of the ALK Positive Lung Cancer (UK) community found that 16% of patients had a blood clot either at diagnosis or shortly after that required them to be prescribed blood thinning medication (Figure 1). This equates to 256 new patients every year in the UK (based on the approximation that there

are 1600 newly diagnosed cases of ALK-positive lung cancer every year). There are differences in approaches to blood thinning medication for those patients who have been prescribed it, with some patients being told it is necessary to take it indefinitely, but others told that it was a short-term treatment (Figure 2).

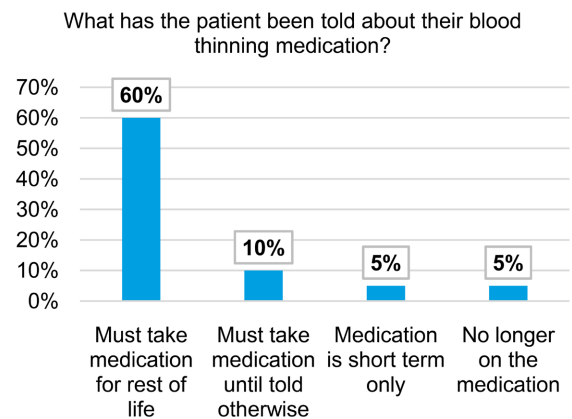


Figure 2. Information on taking blood thinners

Inconsistencies in HCP attitudes towards blood clot risk and subsequent preventative treatment creates a landscape where some patients are at a disadvantage in terms of their overall survival rate. Anticoagulants may improve the survival rate of cancer patients as a preventative measure to avoid developing blood clots, when appropriately weighed up with the risk of bleeding [5].

How many patients are offered brain MRIs every 3 months?
According to region

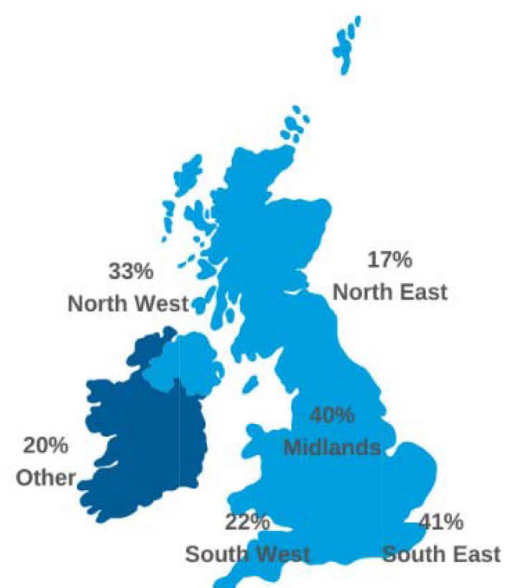


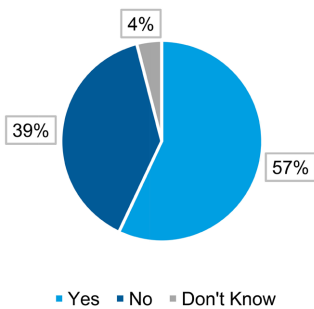
Figure 3. Regional variations in brain MRIs

3.2. Brain Metastases (n = 123)

Brain metastases are more common in patients with ALK-positive lung cancer compared to patients with other NSCLCs [6]. This means that there is a greater need for frequent brain MRIs to detect and diagnose brain metastases. This is not currently part of the standard lung cancer management pathway.

There is a stark health inequality between North and South, 41% of patients reported receiving MRI scans every three months in the south-east, compared to only 17% in the north-east (Figure 3).

Was the patient offered a brain MRI shortly after diagnosis?



Despite the knowledge of increased risk of brain metastases for people with ALK-positive lung cancer, 39% of patients did not receive a brain MRI at or shortly after diagnosis (Figure 4).

38% of patients reported not receiving regular brain MRI scans

Figure 4. Brain MRIs at diagnosis

(Figure 5), meaning that any development of brain metastases post-diagnosis will remain undetected and subsequently untreated, heavily impacting overall survival rates.

Does the patient receive regular brain MRI scans?

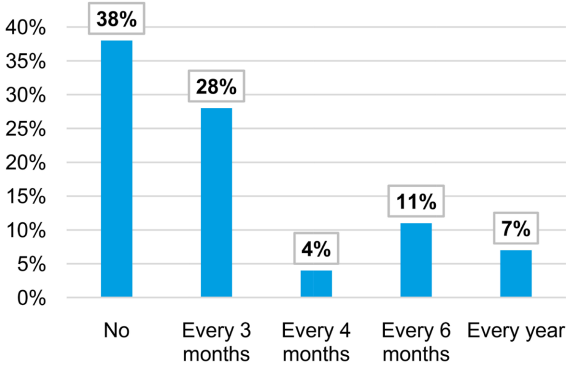
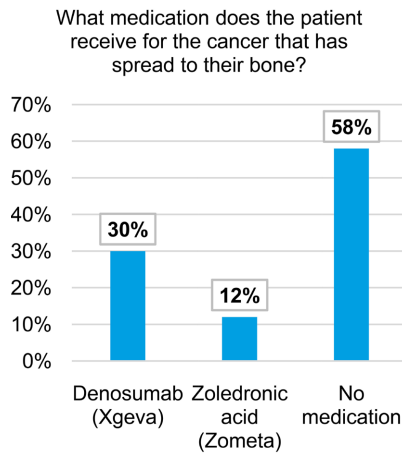


Figure 5. Frequency of brain MRIs

3.3. Bone Metastases (n = 127)

Cancer and its treatments are known to affect bone health [6]. Bone metastases are also common in ALK-positive lung cancer patients (lung cancer is the third most common cause of bone metastases [6]). 31% of patients had found that their cancer had spread to their bones at or shortly after diagnosis. Lung cancer has the lowest 1-year survival rate after bone metastasis (10%) when compared with breast and prostate cancer [7].

Denosumab and Zoledronic acid are two of four bisphosphonates that have approval for managing bone metastases. 42% of patients reported being on



one of these medications. However, 58% of patients reported having bone metastases but not being on any medication (Figure 6).

Figure 6. Bone strengthening medications

3.4. CT & PET Scans (n = 123)

Following a similar thread to that of regular MRI scanning, there are inconsistencies in CT and PET scanning activities. Whilst initial numbers for those receiving regular CT scans are high (93%) (Figure 7), there are inconsistencies with body areas that receive CT scans and, therefore, growth and spread of the cancer may not be detected at the same rate in all patients (Figure 8).

Does the patient receive regular CT scans?

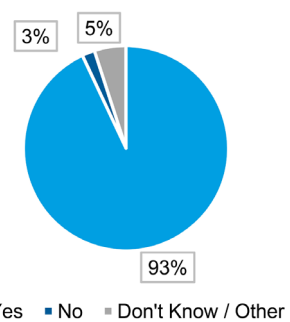


Figure 7. Frequency of CT scans

On what body areas does the patient receive regular CT scans?

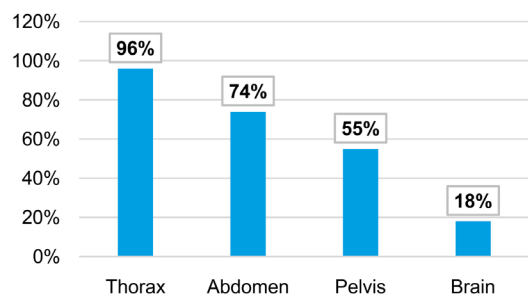


Figure 8. Body areas receiving CT scans

Does the patient receive regular PET scans?

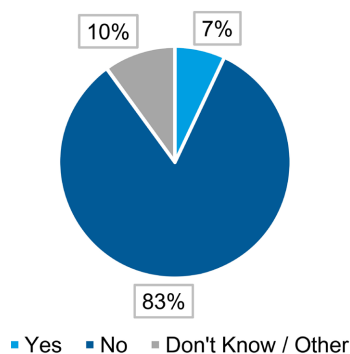


Figure 9. Regular PET scans

In terms of PET scans, which have not been common amongst the ALK-positive community, there are many inconsistencies with the regularity of scans received (Figure 9 and Figure 10). Although more time consuming and potentially more costly than CT scans, PET

scans show molecular activity and assist in identifying the spread of cancer as early as possible. CT scans show the spread of cancer after the event when tissue or organ structure has already been changed.

How often does the patient receive regular PET scans?

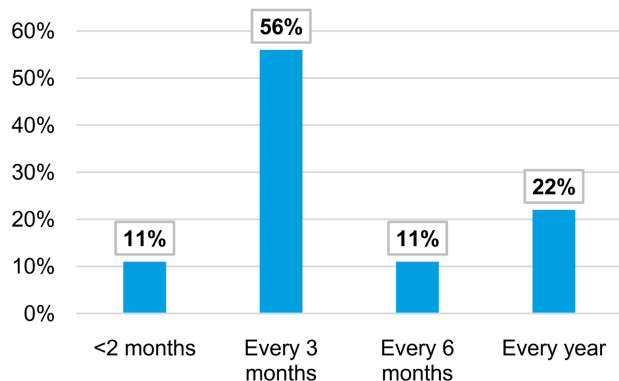


Figure 10. Frequency of PET scans

3.5. Mental Health (n = 132)

The disease management guidelines for any disease or condition in modern times should always address mental health. One in three people with cancer will experience a mental health problem such as depression or anxiety disorders before, during or after treatment [8]. ALK Positive Lung Cancer (UK)'s research found that 60% of patients did not have access, or did not know about access, to counselling at their hospital. Of the patients who did have access and used the services, 77% found it very helpful, and 18% somewhat helpful—proving the value of mental health services. 35% of patients surveyed had used counselling services and 13% had been prescribed medication for depression and/or anxiety since diagnosis, showing that there is an impact of cancer diagnosis on mental health, which should be part of the disease management guideline (further reinforced by findings reported by the Mental Health Foundation [9]).

4. DISCUSSION

Our survey respondents were predominantly female, non-smoking and 84% diagnosed at stage IV of their disease. Whilst there may be some selection bias in terms of the number of women who use Facebook as compared to men, as well as the behavioural bias of women as survey respondents, these data are consistent with what is already known about NSCLC with an oncogene-driver. A recent study based in one large UK hospital found that self-reported never-smokers accounted for 27% of lung cancer cases and 67% of patients were female. In the UK, it is estimated that nearly 6000 never-smokers die of lung cancer every year—greater than the numbers of people who die of cervical cancer (900), lymphoma (5200), leukaemia (4500) and ovarian cancer (4200). Whilst smoking remains the largest modifiable risk factor for lung cancer in the UK, lung cancer in never-smokers is now the eighth most common cause of cancer-related death in the UK if considered as a separate disease, and the seventh most prevalent cancer in the world. According to the Office of National Statistics, nearly nine out of ten (88%) lung cancer patients will survive for at least a year if diagnosed early (stage I), compared to only one-fifth of those who are diagnosed with the most advanced stage of disease.

5. CONCLUSION

The findings, from a representative population of ALK-positive patients, provide new information on the significant disparities in the treatment that patients receive. This health inequality is likely to have a detrimental effect on the survival outcomes for some of these patients. It would improve patient outcomes and overall survival if ALK-positive lung cancer disease management national guidelines were established and utilised across the NHS in the UK. The evidence presented in this report demonstrates the need for a national guideline for the management of ALK-positive lung cancer.

6. ETHICS

No IRB approval was required for this study. The surveys were devised and set up by patients and fully anonymised. Respondents were made aware at the beginning of the surveys that their data would be used in a study on outcomes of the survey.

Acknowledgements

The author would like to thank all the participants who took part in this study.

Authorship

The named author meets the International Committee of Medical Journal Editors (ICMJE) criteria for authorship for this article, takes responsibility for the integrity of the work as a whole, and has given their approval for this version to be published.

Compliance with Ethics Guidelines

The surveys were devised and set up by patients via the platform SurveyMonkey. They were fully anonymised. There was no clinician involvement at any time with the surveys, which were UK based. In compliance with General Data Protection Regulation, only de-identified data were collected; the data fields included in the survey were carefully selected to prevent traceability of the collected data to the identities of individual people. The data were collected and processed solely for the purpose of academic, scientific and medical research undertaken in the public interest. According to the UK Health Research Authority decision tool (<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/access-study-support-advice-services/>) formal IRB approval was not indicated.

Data Availability

The data sets generated and/or analysed during the current study are available from the corresponding author on reasonable request.

Conflicts of Interest

The author declares no conflicts of interest regarding the publication of this paper.

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