



# The Role of UK Oncogene-Focussed Patient Groups in Supporting and Educating Patients with Oncogene-Driven NSCLC: Results from a Patient-Devised Survey

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## ABSTRACT

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. Here, we report findings from a fully anonymised survey conducted in 2020 across the membership of three Facebook-based patient groups in the UK (EGFR Positive UK, ALK Positive UK and ROS-1 Support Group,  $n = 465$ ). Of 167 respondents, most were women (73.1%), never-smokers (60.5%) and diagnosed with stage IV disease (86.3%). Benefits included feeling better prepared (79.6%), being inspired by other members' experiences (71.3%) and being helped with feelings of isolation (49.0%); notably only 27.5% struggled when members died or with feelings of increased anxiety (3%). These findings from a representative population of oncogene-driven NSCLC patients provide new information on the experience of living with lung cancer and highlight the value of specialised support. These patient support groups represent powerful

resources to enable enhanced public and patient engagement and meaningful alliances with key stakeholders to help deliver improvement in outcomes for patients.

**Keywords:** ALK; EGFR; NSCLC; Oncogene-focussed; Patient group; ROS1

### Key Summary Points

This study examines the value and role of oncogene-focussed patient groups in non-small cell lung cancer (NSCLC). Additionally, it evaluates results from a membership survey.

The survey outcomes are assessed to determine whether the membership of these groups is representative of NSCLC patients according to established data.

Data confirm that membership is representative of this patient population and also highlight the value of oncogene-focussed groups for patients.

The study provides new insights on the experience of living with an oncogene-driven lung cancer, the importance of specialised support for patients and the potential for alliances which will deliver meaningful outcomes for patients.

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## DIGITAL FEATURES

This article is published with digital features, including a summary slide, to facilitate understanding of the article. To view digital features for this article, go to <https://doi.org/10.6084/m9.figshare.14039159>.

## INTRODUCTION

In the United Kingdom (UK), lung cancer remains the commonest cause of cancer deaths (approximately 35,100 per year, 2016–2018), accounting for more than 21.0% of all cancer deaths in 2018 [1]. Approximately 25.0% of adenocarcinoma non-small cell lung cancer (NSCLC) cases test positive for an oncogenic driver (epidermal growth factor receptor [EGFR], anaplastic lymphoma kinase [ALK], ROS1, BRAF or NTRK) and can be treated with targeted therapy drugs, whilst others (such as MET, RET and exon 20 insertions) have clinical trial options [2]. In lung cancer with an oncogenic driver, the proportion of women or never-smokers will be higher than in the general lung cancer population [3]. Patient needs specific to this group are currently not met by healthcare professionals and general lung cancer charities and support groups. To address this gap, UK patients and carers have formed oncogene-focussed groups: ALK Positive UK and EGFR Positive UK lung cancer charities, and the ROS1 Support Group (Table 1). These groups are building partnerships which seek to provide support and education, as well as helping patients to access treatment (including clinical trials) through sharing information, treatment pathways and advocacy.

ALK Positive UK and EGFR Positive UK are registered charities founded in 2018 and 2019, respectively. They are run by patients and currently funded by money raised from patients and their families. The ROS1 Support Group was established in 2020. All three groups work with the pharmaceutical and biotech industries to increase awareness of the needs of lung cancer patients, have taken part in NICE technology appraisals as patient experts, and are active on social media networks to promote awareness of

lung cancers with an oncogenic driver, lung cancers among women and never-smokers, and the need to de-stigmatise lung cancer. These thriving patient communities are centred on private Facebook groups, and the ALK Positive UK and EGFR Positive UK lung cancer charities also have websites (Table 1).

Here we describe the purpose and activities of these three UK lung cancer oncogene-focussed groups. In addition, we report results from a recent membership survey aiming to investigate:

- Whether the membership of these patient groups is representative of NSCLC patients with an oncogenic driver according to established data
- How patients accessed these groups
- What value, if any, the groups had for patients
- The emotional impact of being a member of these groups
- How best to expand the services offered by these groups for patients.

## METHODS

Data were gathered through an anonymous membership survey conducted in July 2020. The survey comprised ten questions covering diagnosis, gender, smoking history, and the value of oncogene-focussed patient groups; it was devised jointly by the chairs of the

**Table 1** UK oncogene-focussed lung cancer support groups

ALK Positive UK	hello@alkpositive.org.uk	<a href="http://www.alkpositive.org.uk">www.alkpositive.org.uk</a>
EGFR Positive UK	contact@egfrpositive.org.uk	<a href="http://www.egfrpositive.org.uk">www.egfrpositive.org.uk</a>
ROS-1 Support Group	ros1positive@gmail.com	

oncogene-focussed groups. The survey was made available to all members via Facebook, since this is the primary communications platform for all three organisations. These are closed groups, intended for patients and carers. The survey was generated by SurveyMonkey.com and was posted three times over a 2-week period. Respondents were able to move on to the next question even if they chose not to answer a particular question.

### Ethics

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

## RESULTS

Out of the 465 members across all three groups at the time of the survey, 167 patients or carers completed all survey questions (ALK Positive UK, 89; EGFR Positive UK 74, and ROS1 Support Group, 4). This differential response rate is consistent with membership of the respective groups at the time of survey (ALK Positive UK, 300; EGFR Positive UK, 157 and ROS1, 8).

The majority of respondents were female (73.1%) and never-smokers (60.5%). The overwhelming majority of respondents were diagnosed at stage IV (86.3%). Despite the considerable benefit and availability of targeted therapies, diagnosis at this stage of disease offers no chance of curative treatment, and patient outcomes are poorer. Only 57.5% of respondents were diagnosed via general practitioner (GP) referral, leaving 42.6% diagnosed via accident and emergency (A&E) department or other routes (Table 2).

Three-quarters of respondents (75.5%) had accessed other support groups including national groups and other online forums, showing the importance of support for patients dealing with a diagnosis of lung cancer. This is clearly a group of patients motivated to access support and information. A significant

proportion of respondents (87.8%) found mutation-specific support groups to provide better support and placed higher values on group discussions than other support groups (Table 3).

This reflects both the need for information about oncogene-specific treatments not available from other sources, and the importance of support from other patients with the same lung cancer mutation. Membership in these groups resulted in 79.6% of respondents feeling better prepared and informed, while 49.0% felt it had helped with feelings of isolation, and 72.5% would recommend the group to another patient in a similar situation. A significant challenge associated with being part of a patient group is dealing with the death of other members of the group. Yet surprisingly, whilst 27.5% struggled when members died, only 3% felt that membership in a group increased their anxiety, compared with 71.3% feeling inspired by other members' experiences (Fig. 1).

**Table 2** Patient characteristics

	<i>n</i>	%
Gender		
Female	122	73.1
Male	45	26.9
Stage at diagnosis		
I/II	6	3.6
III	12	7.1
IV	145	86.3
Do not know	5	3.0
Where diagnosed		
A and E	37	22.2
GP referral	96	57.5
Other	34	20.4
Smoking history		
Regular smoker	8	4.8
Past smoker/non-smoker	58	34.7
Never smoker	101	60.5

**Table 3** Use of other support groups, and how oncogene-focussed groups compare

	<i>n</i>	%
Survey respondent		
Patient	128	76.2
Family/friend	49	23.8
Have you used other support groups?		
Local	30	18.0
National	33	19.8
Online	63	37.7
None	55	32.9
How does this group compare with others?		
Much better	83	59.7
Better	39	28.1
About the same	16	11.5
Worse	0	0.0
Much worse	1	0.7
How valuable are the group discussions?		
Extremely valuable	104	62.7
Very valuable	48	28.9
Somewhat valuable	14	8.4
Not at all valuable	0	0.0

## DISCUSSION

Our survey respondents were predominantly female, non-smoking and nearly 90% 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 [4].

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) [5]. Whilst smoking remains the largest modifiable risk factor for lung cancer in the UK, accounting for 86% of lung cancers, 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 [6].

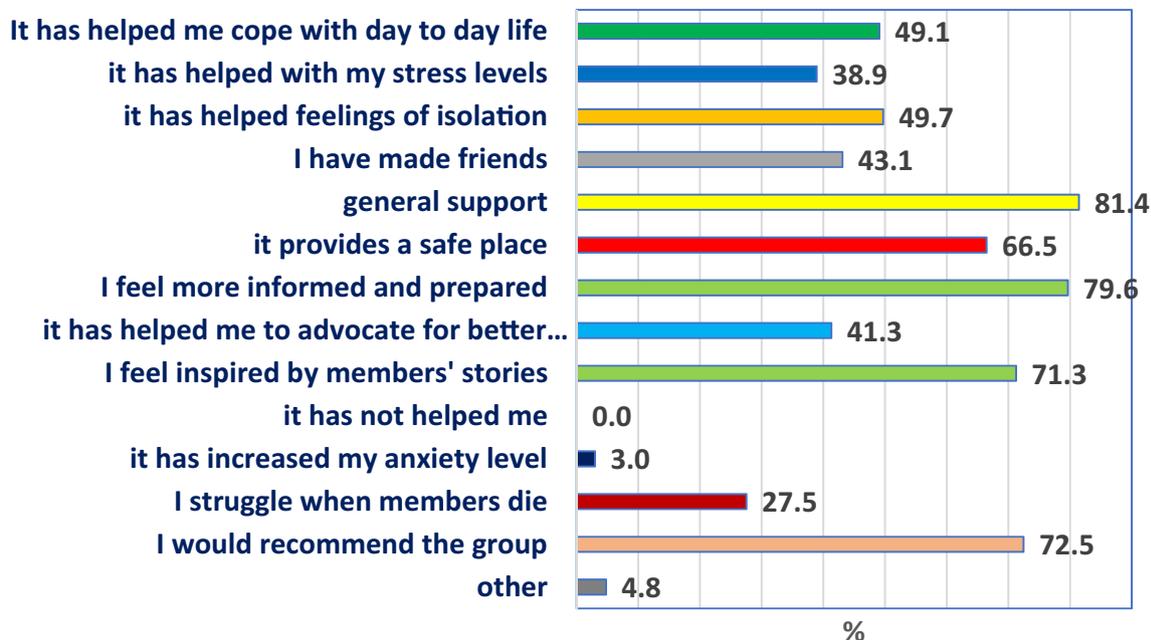
According to the Office of National Statistics, nearly nine out of ten (88%) lung cancer patients will survive for at least a year if diagnosed early (stage I), compared to only one-fifth of those who are diagnosed with the most advanced stage of disease [7].

Data from the National Lung Cancer Audit reported that in 2017, 57% of patients had stage IIIB or stage IV disease at the point of presentation [8]. This percentage is significantly higher than in other cancer types. For lung cancer with an oncogenic driver and a higher prevalence of never-smokers, early diagnosis is challenging, and there can be low awareness of symptoms and signs. This may be partly driven by a perception that lung cancer is exclusively a smokers' disease, despite 10–15% of patients never having smoked [9], leading to under-recognition of the disease in never-smokers. Furthermore, patients are often younger than the general lung cancer population.

In England, around 40% of people with lung cancer first reach specialist care via an emergency admission to hospital [10], which is line with the findings of this survey. Earlier diagnosis saves lives, and more work is needed to understand why so many lung cancers are diagnosed via the emergency route. Anecdotally, patients talk about the delays in recognising their symptoms as being those associated with lung cancer.

Sharing information and encouraging patient advocacy is a key part of the work of the three oncogene-focussed groups, with members contributing their own treatment pathways, experiences of clinical trials, and a significant body of knowledge on dealing with treatment side effects. Often, patients become experts in their own disease [11], particularly with the rarer cancers. Patients and their families join these groups because they perceive that their

### How do you feel about being a member of the group?



**Fig. 1** How respondents feel about being a member of their oncogene-focussed support group (participants could answer yes to more than one question)

chances improve if they learn as much about their disease and treatment options as possible. This notion is supported by findings here where patients report feeling better informed and prepared as a result of belonging to our groups.

Patients are also keen to accelerate research and access to treatment—in the UK, access to targeted therapy drugs is a key issue for patients who have lung cancer with an oncogenic driver. Patients have been able to contribute to NICE technology appraisals as part of group submissions and have lobbied Members of Parliament (MPs) for increased funding for lung cancer. They have also been part of a campaign to raise awareness of lung cancer symptoms amongst GPs.

This is the first patient survey across our membership and is exploratory in nature. Findings raise important questions that need further research to robustly address including whether value and experience of membership is influenced by age, sex or point in an individual’s disease journey. In addition, although most respondents rated membership in

oncogene-specific groups as being of greater value than others, this may reflect a biased sample and may not be generalisable to all patients with an oncogenic-driven lung cancer. Understanding more about those who did not participate in our survey, as well as the membership and experience of people that belong to other patient support groups, will help to better describe the landscape and value of the patient voice.

### CONCLUSION

We have outlined findings from the first joint membership survey of ALK Positive UK, EGFR Positive UK and the ROS-1 UK Support Group. The membership of these three groups appears to be representative of the patient population with lung cancer and an oncogenic driver. Responses to the survey indicate that these oncogene-focussed groups represent a unique and valuable resource for patients, providing new information on the experience of living

with an oncogenic-driven lung cancer, and highlighting the need for support in this patient population.

However, the survey shows evidence that more could be achieved in terms of supporting patients: less than half of respondents felt that membership in a group helped them advocate for better care. It is also clear that a large proportion of patients still struggle with feelings of isolation despite the support offered by groups, perhaps reflecting the stigma and discrimination associated with lung cancer in society at large.

With nearly 500 members, and membership growing every week, there is clearly scope for further collaboration to address questions which are meaningful to patients and that accommodate patients' real-world experiences of living with an oncogene-driven lung cancer. Working with patients and understanding patient needs offers significant opportunities which will help deliver meaningful outcomes that extend and save lives. Researchers, clinicians, the pharmaceutical industry and other lung cancer organisations can all help improve outcomes for patients by partnering with patient groups and helping them to thrive and grow. All stakeholders in the lung cancer community could benefit from these alliances.

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**Disclosures.** Jenny Abbott, Kathleen Beattie and Debra Montague have nothing to disclose.

**Compliance with Ethics Guidelines.** The survey was devised and set up by patients via the platform SurveyMonkey. It was fully anonymised and introduced to patient members in the following way: *'Now we have got to a significant size we would like to ask all members—patients and carers—to do this short survey to help us understand more about our members, what we offer as a group and what we might improve. It is anonymous, only ten questions and takes under two minutes. ALK Positive UK and EGFR Positive UK also hope to use the results to write a review for an oncology journal on the role of support groups in mutation-driven lung cancers—a good way to raise the issues around these types of lung cancers and the concerns of patients'*. There was no clinician involvement at any time with the survey, which was 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 (<http://www.hra-decisiontools.org.uk/ethics/index.html>) formal IRB approval was not indicated.

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

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