

The Role of UK Oncogene-Focussed Patient Groups in Supporting and Educating Patients with Oncogene- Driven NSCLC.

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Abstract

To meet the needs of a patient body comprised of non-small cell lung cancer (NSCLC) patients with an oncogene-driver, patients have organised into support groups. These groups are building partnerships which seek to provide support and education for patients as well as helping patients to access treatment through sharing information and promoting advocacy. Here, the value of these groups to patients is examined and the results of a membership survey assessed to determine if the membership of these oncogene-focussed groups is representative of NSCLC patients with an oncogenic-driver according to established data. The survey provides new information on the experience of living with on oncogenic-driven lung cancer and the importance of specialised support for this population of NSCLC patients. We also highlight the potential of these groups as resources for further alliances which will help deliver meaningful outcomes for patients.

Key Words Patient Group ▪ Oncogene-Focussed ▪ NSCLC

INTRODUCTION

In the United Kingdom (UK), lung cancer remains the commonest cause of cancer deaths (approximately 35,300 per year, 2015-2017), accounting for more than 21.0% of all cancer deaths in 2017¹. 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 options². In lung cancer with an oncogenic driver, the proportion of women or never-smokers will be higher than in the general lung cancer population³. Patient needs specific to this group are currently not met by healthcare

¹ Cancer Research UK mortality statistics accessed at: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality/common-cancers-compared#heading-Zero>

² Pakkala S, Ramalingam SS. Personalized therapy for lung cancer: striking a moving target. *JCI Insight*. 2018 Aug 9; 3(15):e120858. doi: 10.1172/jci.insight.120858. PMID: 30089719; PMCID: PMC6129126.

³ Rudin CM, Avila-Tang E, Harris CC, et al. Lung cancer in never smokers: molecular profiles and therapeutic implications. *Clin Cancer Res*. 2009;15(18):5646-5661. doi:10.1158/1078-0432.CCR-09-0377

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	hello@alkpositive.co.uk	www.alkpositive.co.uk
EGFR Positive UK	contact@egfrpositive.org.uk.	www.egfrpositive.org.uk
ROS-1 Support Group	ros1positive@gmail.com	

Table 1. UK Oncogene-Focussed Lung Cancer Support Groups

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.

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 was gathered through an anonymous membership survey conducted in July 2020. The survey comprised of ten questions covering diagnosis, gender, smoking history, and the value of oncogene-focussed patient groups; it was devised jointly by the Chairs of the 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 two-week period. Respondents were able to move onto the next question even if they chose not to answer a particular question.

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 GP referral, leaving 42.6% diagnosed via A&E or other routes (Table 2).

	n	%
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
Don't know	5	3.0
Where diagnosed		
A&E	37	22.2
GP referral	96	57.5
Other	34	20.4
Smoking history		
Regular smoker	8	4.8
Smoker years ago	58	34.7
Never smoked	101	60.5

Table 2. Patient characteristics

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).

	n	%
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

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

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 of 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 of being part of a patient group is dealing with death of other members of the group. Yet surprisingly, whilst 27.5% struggled when members died, only 3% felt that membership of a group increased their anxiety, compared with 71.3% feeling inspired by other members' experiences (Figure 1).

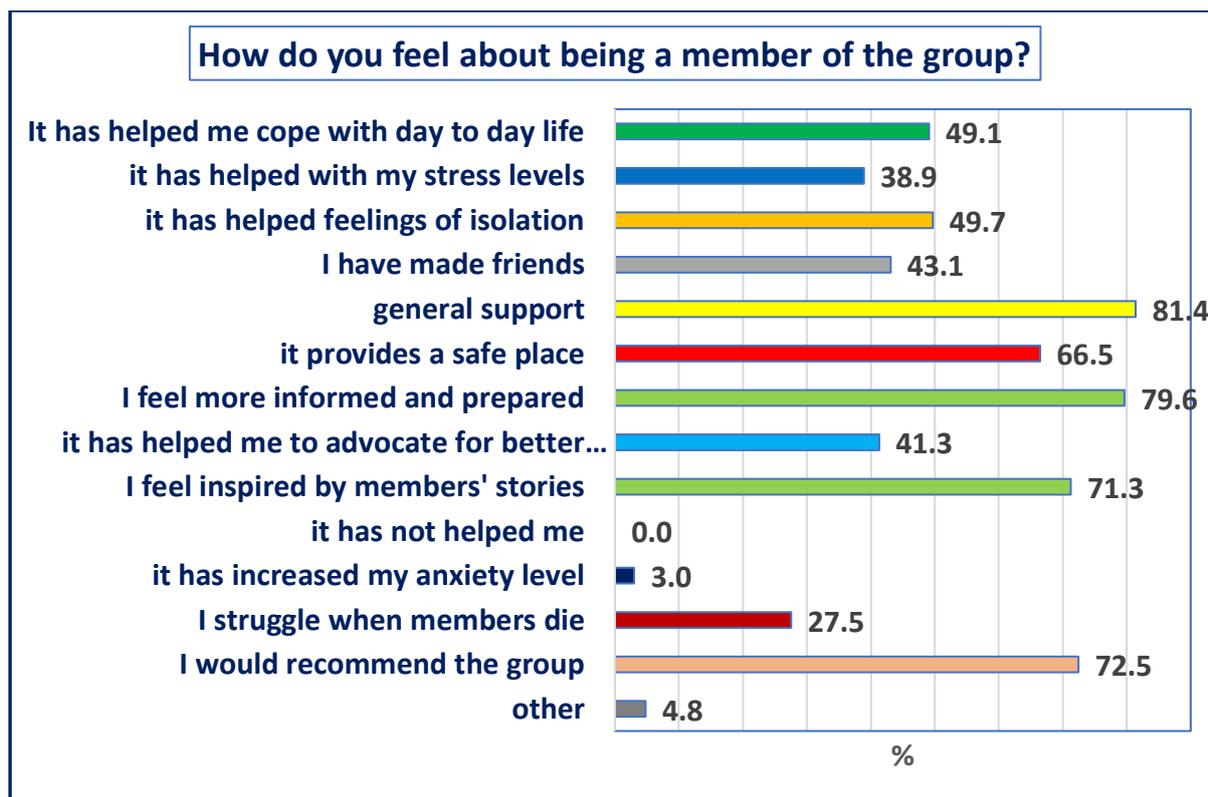


Fig. 1. How respondents feel about being a member of their oncogene-focused support group.

(note: participants could answer yes to more than one question)

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 female⁴.

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

⁴ Cufari ME, Proli C, De Sousa P, Raubenheimer H, Al Sahaf M, Chavan H, Shedden L, Niwaz Z, Leung M, Nicholson AG, Anikin V, Beddow E, McGonigle N, Dusmet ME, Jordan S, Ladas G, Lim E. Increasing frequency of non-smoking lung cancer: Presentation of patients with early disease to a tertiary institution in the UK. *Eur J Cancer*. 2017 Oct;84:55-59. doi: 10.1016/j.ejca.2017.06.031. Epub 2017 Aug 4. PMID: 28783541.

⁵ Cancer Research UK statistics accessed at <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/lung-cancer?script=true#heading-Zero>

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 world⁶.

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 1), compared to only one fifth who are diagnosed with the most advanced stage of disease⁷.

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 presentation⁸. 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 smoked⁹, 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 hospital¹⁰, 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 disease¹¹, particularly with the rarer cancers. Patients and their families join these groups because they perceive that their chances improve if they learn as

⁶ Bhopal A, Peake MD, Gilligan D, Cosford P. Lung cancer in never-smokers: a hidden disease. *Journal of the Royal Society of Medicine*. 2019;112(7):269-271. doi:10.1177/0141076819843654

⁷ ONS, Cancer survival in England: national estimates for patients followed up to 2018, 2019. Available via: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinengland/stageatdiagnosisandchildhoodpatientsfollowedupto2018>

⁸ Royal College of Pathologists, National Lung Cancer Audit, Annual Report 2018 (for the audit period 2017), May 2019

⁹ Science Surgery: 'Why do never-smokers get lung cancer?', CRUK, 2018. Available via <https://scienceblog.cancerresearchuk.org/2018/11/16/science-surgery-why-do-never-smokers-get-lung-cancer/>

¹⁰ *Early Diagnosis Matters, Making the Case for the Early and Rapid Diagnosis of Lung Cancer*. Available at UKLCC.org.uk.

¹¹ @JackWestMD. "Time to highlight that we are now in an era when pts w/rare cancers are increasingly likely to know more than docs, even very good ones, about their dzs. This @ros1cancer page on Drugs to Treat ROS1+ NSCLC deserves its place at top of Google search: bit.ly/ROS1Rxs #LCSM." *Twitter* <https://twitter.com/JackWestMD/status/989287575469805568> (2018).

much about their disease and treatment options as possible. This is certainly borne out by the number of patients who feel better informed and prepared as a result of belonging to a group.

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 MPs for increased funding for lung cancer. They have also been part of a campaign to raise awareness of lung cancer symptoms amongst GPs.

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 in lung cancer with 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 also be achieved in terms of supporting patients: less than half of respondents felt that membership of 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 five hundred 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.