ALK Positive Lung Cancer (UK)

The Demographics of ALK-positive NSCLC patients in the UK and Ireland

Disclaimer

This report presents the findings of a survey of people affected by lung cancer and reflects the experiences and views of those who took part. The findings should not be assumed to represent the views or experiences of all people affected by lung cancer.

The information in this report is provided for general information purposes and should not be regarded as medical advice, diagnosis, or a substitute for advice from a qualified healthcare professional. Anyone with concerns about their health should seek advice from an appropriate healthcare professional.

Every effort has been made to ensure that the information and analysis presented in this report are accurate at the time of publication. However, survey findings are subject to the limitations of the survey methodology, including the number and characteristics of respondents and the possibility of response and selection bias. ALK Positive Lung Cancer (UK)accepts no liability for any loss or harm arising from reliance on the information contained in this report.

Patient confidentiality

ALK Positive Lung Cancer (UK) is committed to protecting the privacy of everyone who took part in the survey and individual respondents are not identified in this report.

Contents

Acknowledgements

ALK Positive UK thanks all patients, carers, and family members who took the time to complete this survey. Your experiences are invaluable in shaping a better real-world understanding of ALK-positive NSCLC in the UK and in driving improvements in care.

We also thank our clinical advisors, volunteers, and all those who contributed to the design, promotion, and administration of the survey and to the production of this report

1. About ALK Positive Lung Cancer (UK)

ALK Positive Lung Cancer (UK), also known as ALK Positive UK, has been a registered charity since 2018. The charity is patient-led and patient-focused.

Our mission is:

- to support patients and their families who are living with ALK-positive lung cancer;
- to empower them so that they can meaningfully engage in shared-decision making with their healthcare providers; and
- to advocate for improvements in the diagnosis, treatment and care of ALK-positive lung cancer patients throughout the UK.

We also campaign to raise awareness of non-smoking lung cancer and for early diagnosis.

We carry out surveys of the members of our Support Group to gather real-world data on how patients were diagnosed and the treatment and care that they receive. We use the data from these surveys to improve the services that we offer to members, to identify gaps in best practice and to advocate nationally.

2. Introduction

ALK-positive non-small cell lung cancer (NSCLC) is found in about 3% of all lung cancers [1]. It has a distinctive patient profile: it occurs predominantly in younger people, women, and never-smokers, and it is typically diagnosed at an advanced, metastatic stage [2]. Despite representing a relatively small proportion of all lung cancer diagnoses, it carries significant consequences for patients, families, and the healthcare system — not least because those it affects are often in the prime of their working and family lives.

In 2026, ALK-positive patients or caregivers across the United Kingdom and Ireland participated in a survey to gather real-world evidence of their diagnosis, treatment and care. The results of the survey will be presented in four focused reports:

- Demographics
- Diagnosis
- Treatment
- Care

This first report is about the demographics of ALK-positive patients and includes data on age, sex, geography, ethnicity, smoking history, stage at diagnosis, employment impact, pre-existing conditions and caring responsibilities.

The findings carry implications that extend beyond academic interest. For clinicians, they illuminate the real-world profile of patients in routine practice. For commissioners and policymakers, they highlight the economic and social dimensions of a diagnosis that disproportionately affects working-age adults with dependants. And for the ALK-positive community itself, they offer a mirror — a population-level reflection of experiences that are often lived in isolation.

3. Method

This survey was administered online and distributed by ALK Positive UK to its members and communities, including its Facebook support group. Participation was open to patients with a confirmed diagnosis of ALK-positive NSCLC, and to family members or carers completing the survey on behalf of a patient.

The survey was completed by 180 respondents, comprising 162 (90%) patients and 18 (10%) caregivers and is the most comprehensive survey of this patient population conducted by ALK Positive UK to date.

180

ALK-positive NSCLC participants

162

patients (90%)

18

caregivers (10%)

All data are self-reported and have not been verified against medical records. Where questions permitted multiple responses, totals may exceed 180. Percentages are rounded to the nearest whole number. For age at diagnosis, median and mean values were estimated using the midpoint of each age band (70+ treated as 73). No data have been excluded from this report.

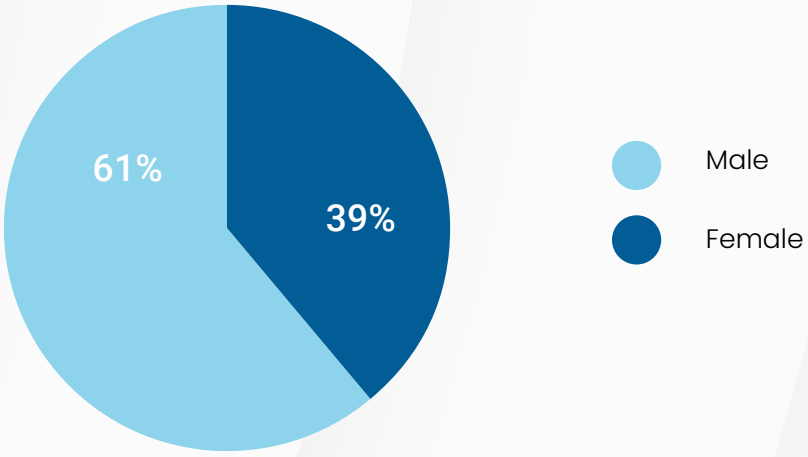
4. Summary of key findings

Finding	n	Percentage	Note
Female sex	109 / 180	61%	
Median age at diagnosis	57 years		
Never / minimal smoker	121 / 180	67%	
Diagnosed at Stage 4	148 / 180	82%	
No pre-existing conditions	101 / 180	56%	
Working at time of diagnosis	130 / 180	72%	
Reduced hours due to cancer	89 / 130	68%	of those working
Stopped working due to cancer	66 / 130	51%	of those working
Had caring responsibilities	90 / 180	50%	
Caring for child aged 5–17	51 / 180	28%	
Caring for parent(s)	41 / 180	23%	
White ethnicity	163 / 180	91%	

5. Sex

Of 180 respondents, 109 (61%) were female and 71 (39%) were male. The proportion of females is consistent with the 57% reported in other studies [2].

Figure 1. Sex of respondents at birth (n=180).



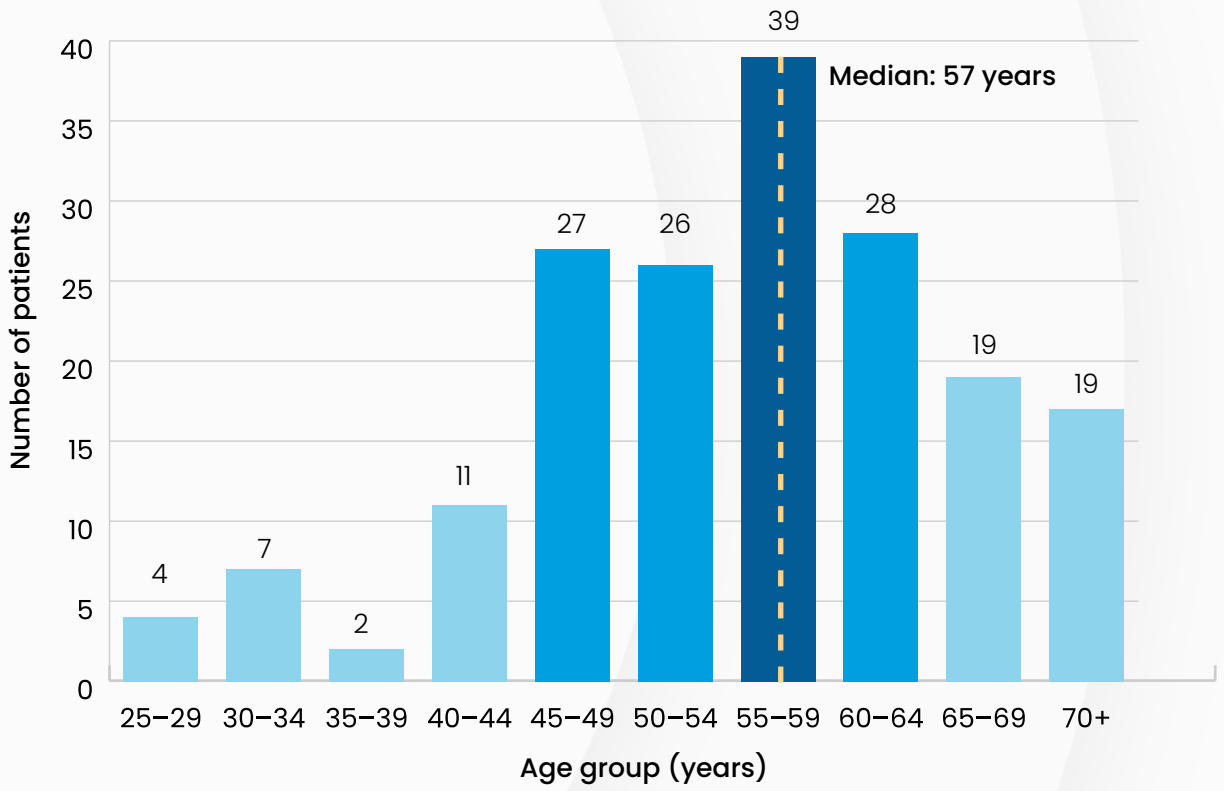
6. Age at diagnosis

Respondents were asked to indicate their age group at the time of their lung cancer diagnosis. The largest single group was the 55–59 bracket (39 patients, 22%), closely followed by 60–64 (28 patients, 16%) and 45–49 (27 patients, 15%).

Median age at diagnosis: 57 years
Mean age at diagnosis: 55.3 years

ALK-positive NSCLC characteristically affects a younger population than other lung cancer. Half the patients were under the age of 57 years and half were over.

Figure 2. Age distribution of respondents at diagnosis (n=180). Dashed line indicates median age (57 years).

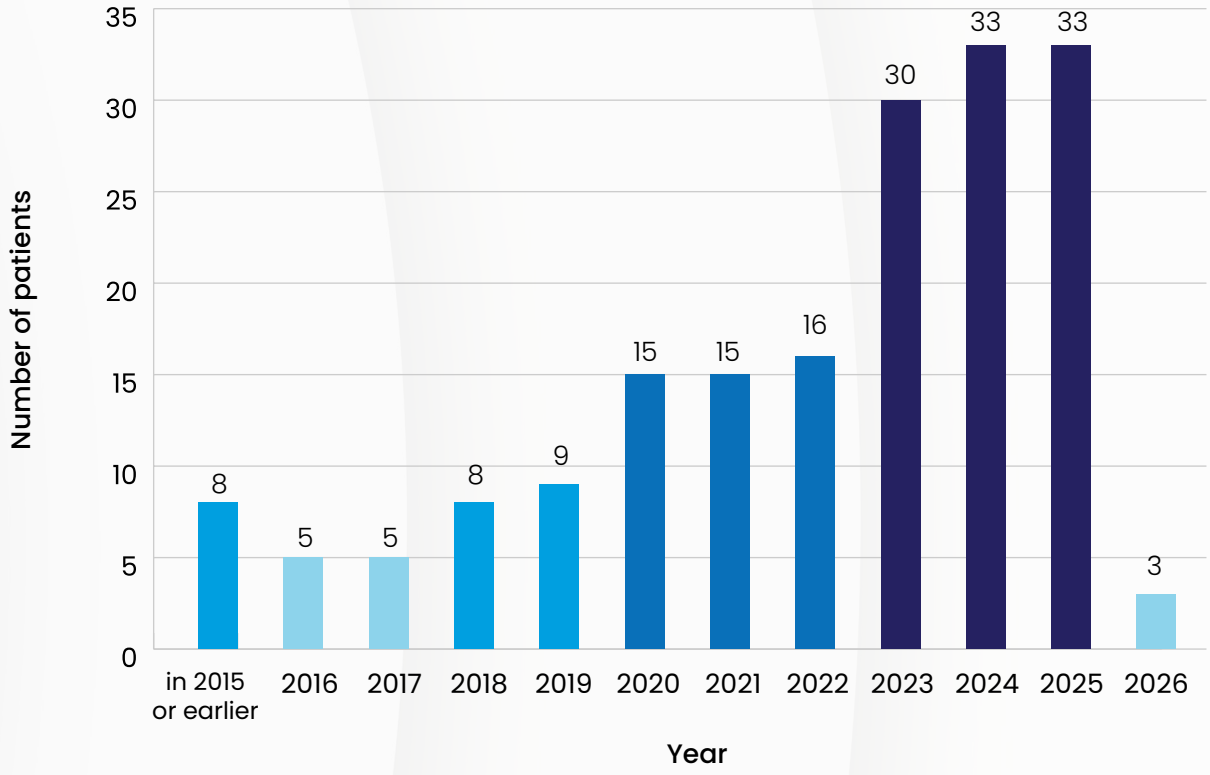


ALK Positive UK's unpublished data on 478 patients shows a median age at diagnosis of 52 years, which is consistent with other published data [2]. The median age at diagnosis of all lung cancer patients is about 74 years [3].

7. Year of diagnosis

The survey captures patients diagnosed over more than a decade, from 2010 to 2026. The majority received their diagnosis in 2023 or 2024 (30 and 33 patients respectively), reflecting both growing disease awareness and the expansion of the ALK Positive UK community. Eight patients were diagnosed in 2015 or earlier, demonstrating that long-term survival is achievable with targeted therapy.

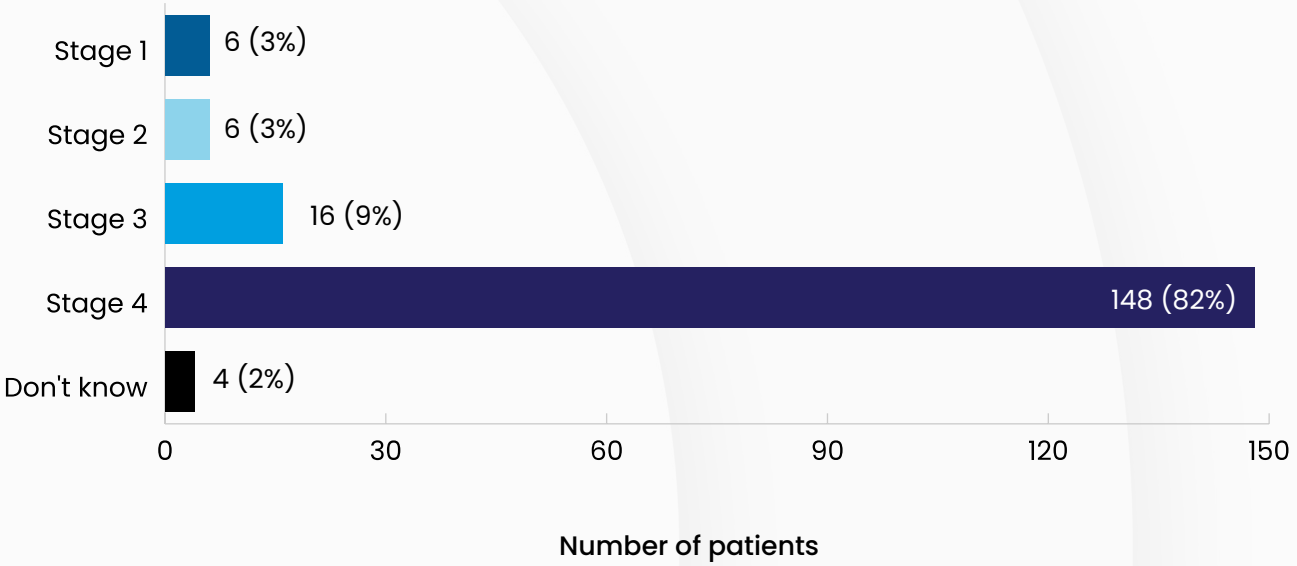
Figure 3. Year of lung cancer diagnosis (n=181)



8. Stage at diagnosis

Stage at diagnosis is among the most consequential clinical variables in lung cancer. The findings are stark: 148 of 180 respondents (82%) were diagnosed at stage 4 — advanced, metastatic disease. A further 16 (9%) were diagnosed at stage 3. Only 12 patients (7%) presented at potentially curable stages 1 or 2. The proportion of patients diagnosed at Stage 4 is similar to that reported in other studies [2].

Figure 4. Stage at diagnosis (n=180).

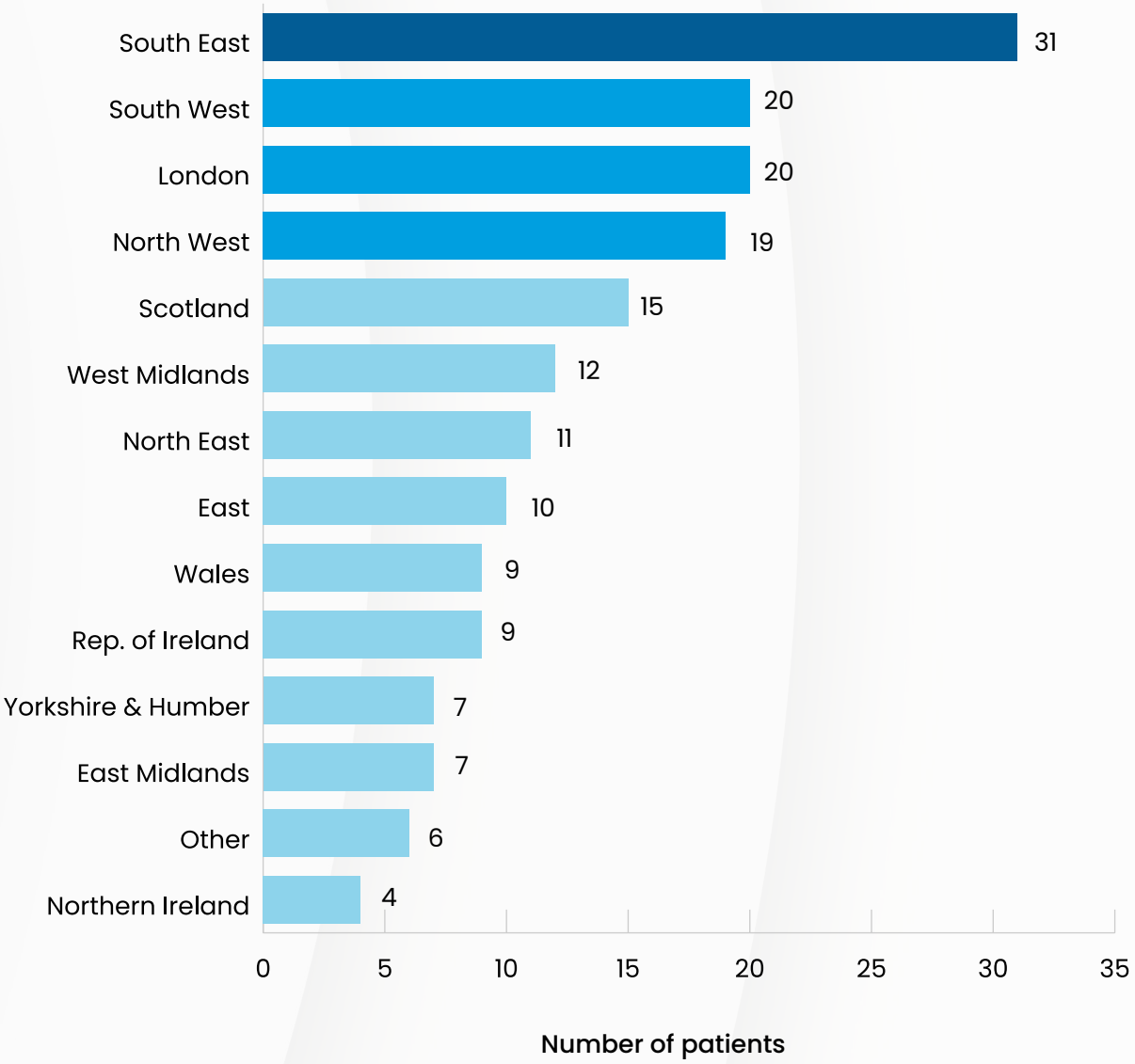


9. Location

Respondents were distributed across 13 named UK regions plus the Republic of Ireland. The highest representation came from the Southeast and London (51 patients, 28%).

Figure 5. Geographic distribution of respondents (n=180)

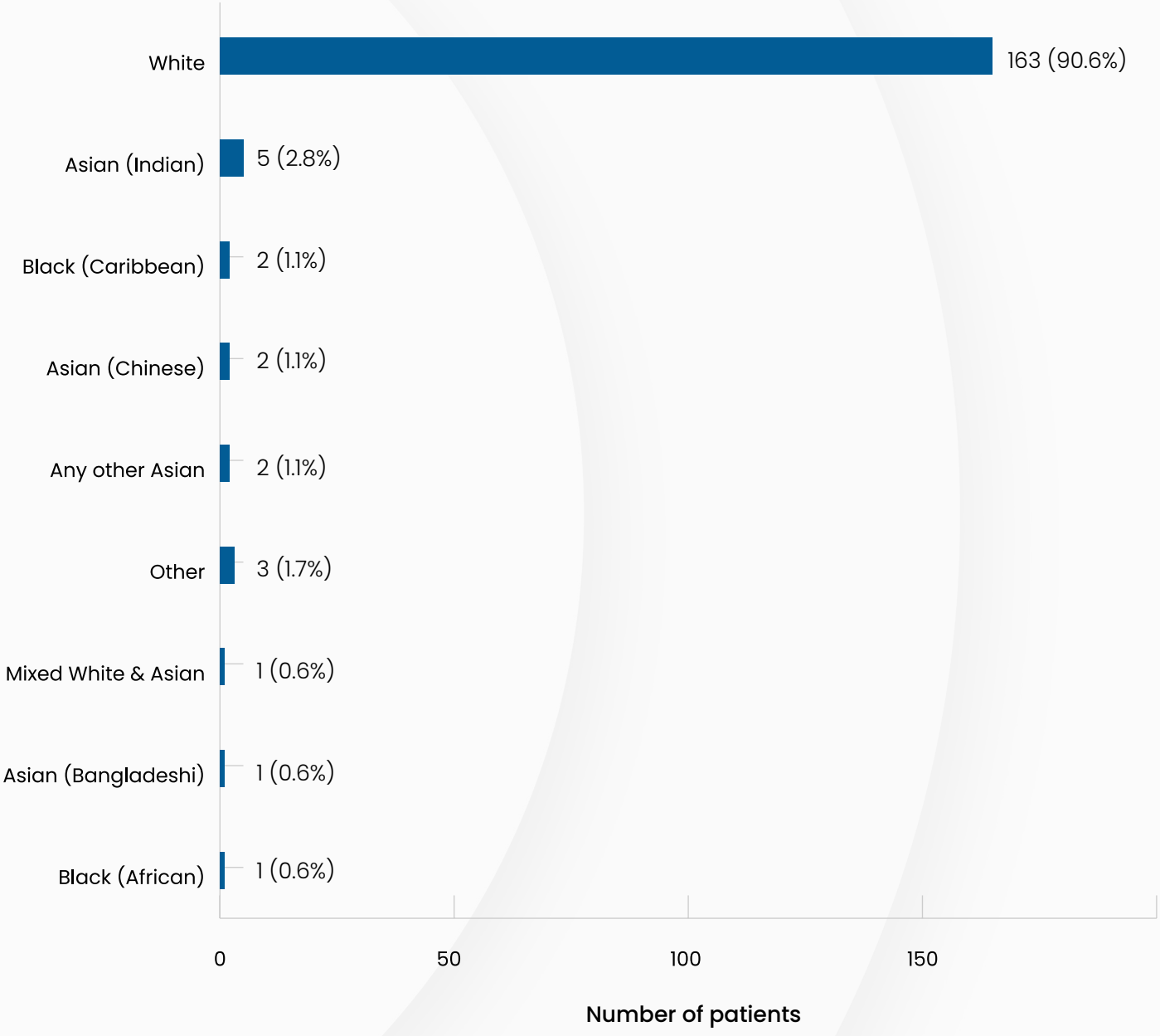
The proportion of respondents living in the Southeast and London (28%) is less than the proportion of UK residents [3].



10. Ethnicity

The survey population was predominantly White (163/180, 91%). Asian-background patients accounted for 10 respondents (6%), including Indian (5), Chinese (2), Bangladeshi (1), and other Asian (2). Black and mixed-heritage patients made up the remainder.

Figure 6. Self-reported ethnicity of respondents (n=180).



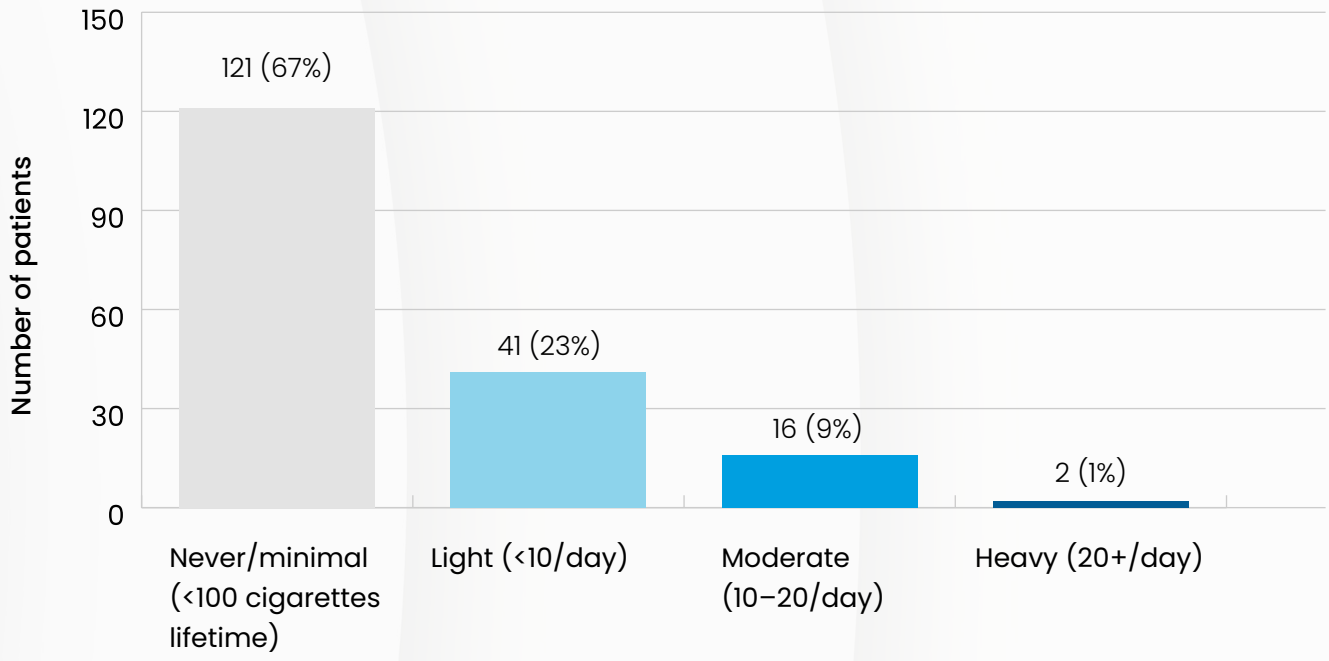
The proportion of white respondents (91%) is above the estimated 86–88% of white people between the ages of 25 and 75 in the UK [4].

11. Smoking history

One of the most striking characteristics of ALK-positive NSCLC is its occurrence in never-smokers or light smokers. This survey confirms that pattern clearly: 121 of 180 respondents (67%) had never smoked or smoked fewer than 100 cigarettes in their lifetime. A further 41 (23%) had a light smoking history. Only 18 patients (10%) had a moderate or heavy smoking history.

In the general population, smoking is responsible for 70% of lung cancer cases [2].

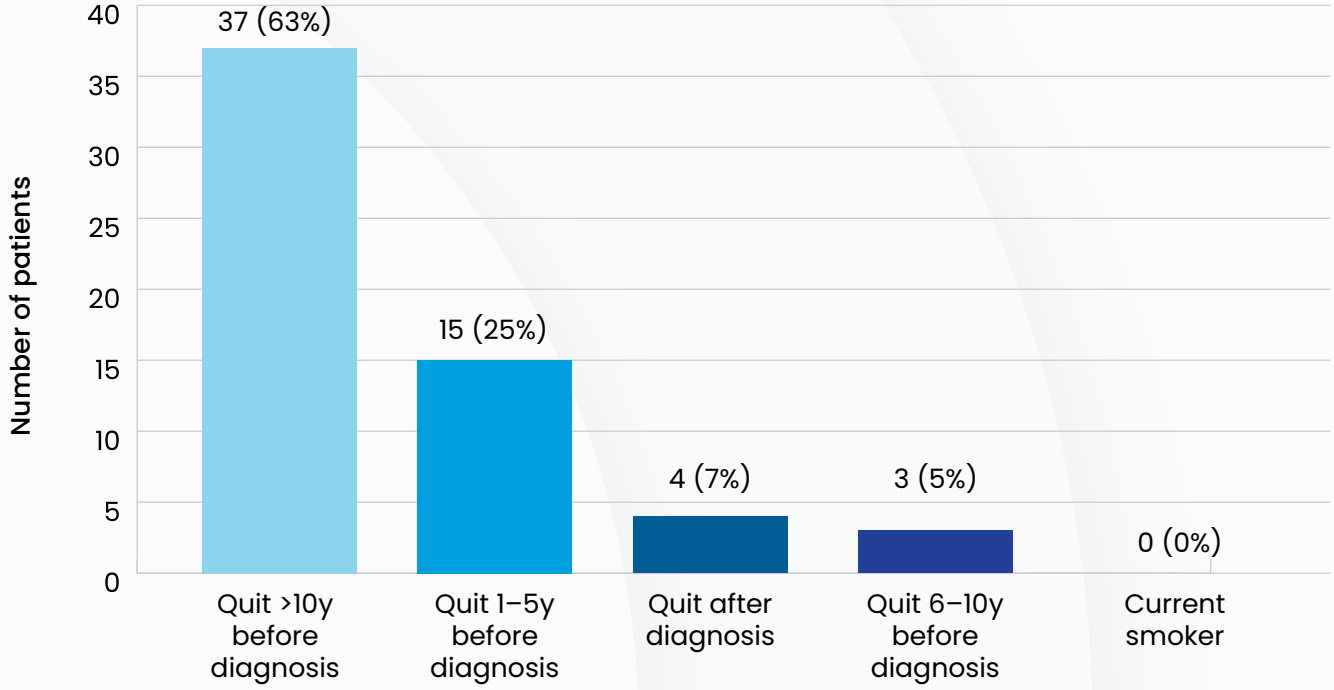
Figure 7. Smoking history of respondents (n=180).



This non-smoking profile has important implications for public awareness: ALK-positive lung cancer can affect people who have never smoked, challenging the widespread assumption that lung cancer is a disease of smokers.

Current smoking status

Figure 8. Current smoking status of 59 respondents with a smoking history



Among the 59 respondents with a smoking history (excluding the 121 who never smoked):

- 37 (63%) quit more than 10 years before diagnosis
- 15 (25%) quit 1–5 years before diagnosis
- 4 (7%) quit after diagnosis
- 3 (5%) quit 6–10 years before diagnosis
- 0 (0%) current smokers — included explicitly to show the nil count

So, among those who ever smoked, nearly two-thirds had quit at least a decade before their diagnosis, and not a single respondent in the entire survey identified as a current smoker.

12. Employment status

The economic impact of an ALK-positive NSCLC diagnosis on employment is substantial. Of 180 respondents, 130 (72%) were working at the time of diagnosis. Among this group:

1. 89 of 130 working patients (68%) reduced their working hours as a result of their diagnosis or treatment.
2. 66 of 130 working patients (51%) stopped working altogether because of the effects of their lung cancer
3. The high rate of work cessation — affecting one in two employed patients — has significant financial implications

Figure 9. Employment impact of diagnosis. Left: working status at diagnosis (n=180). Centre: hours reduction among those working (n=89). Right: work cessation among those working (n=89).

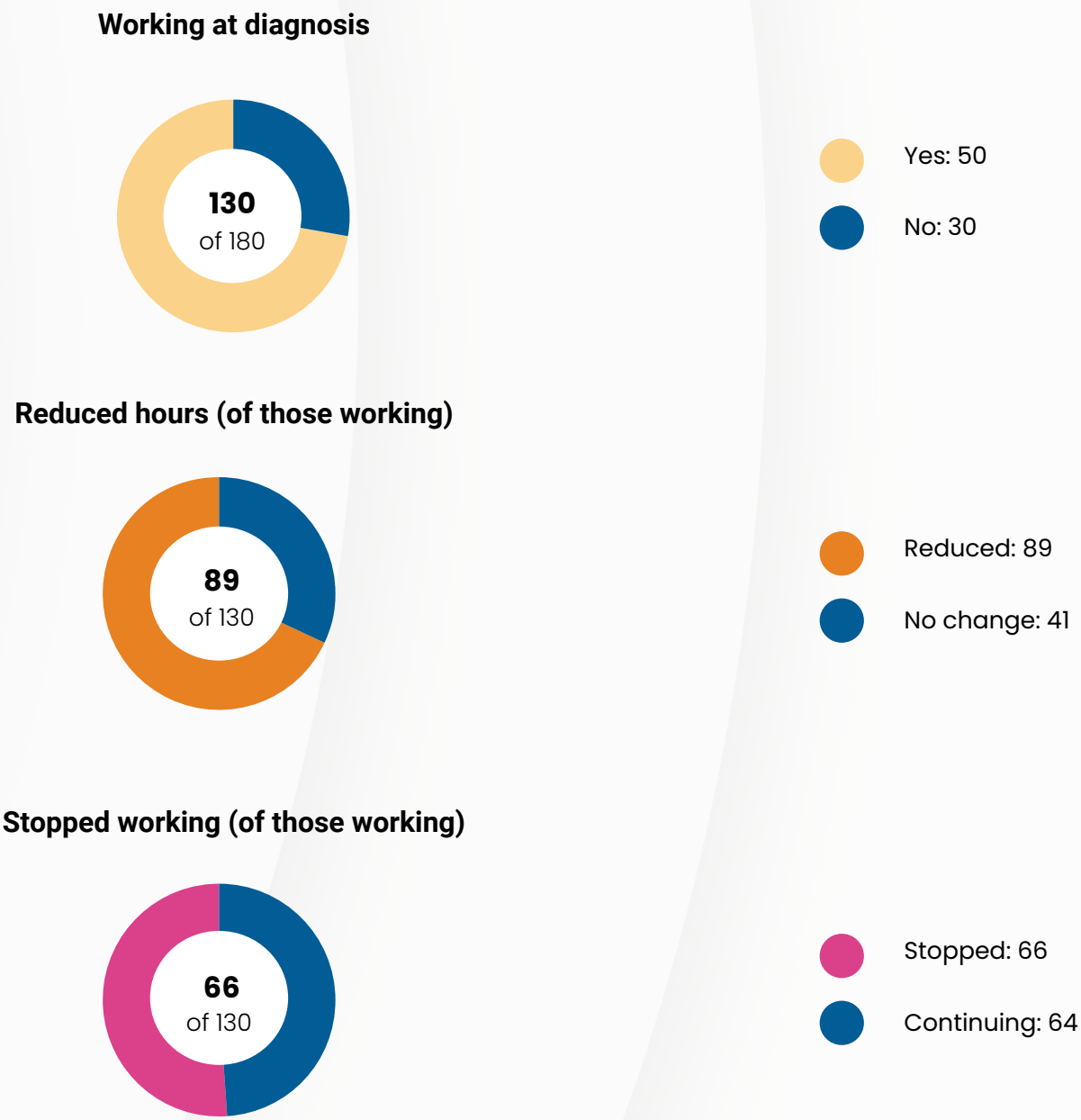
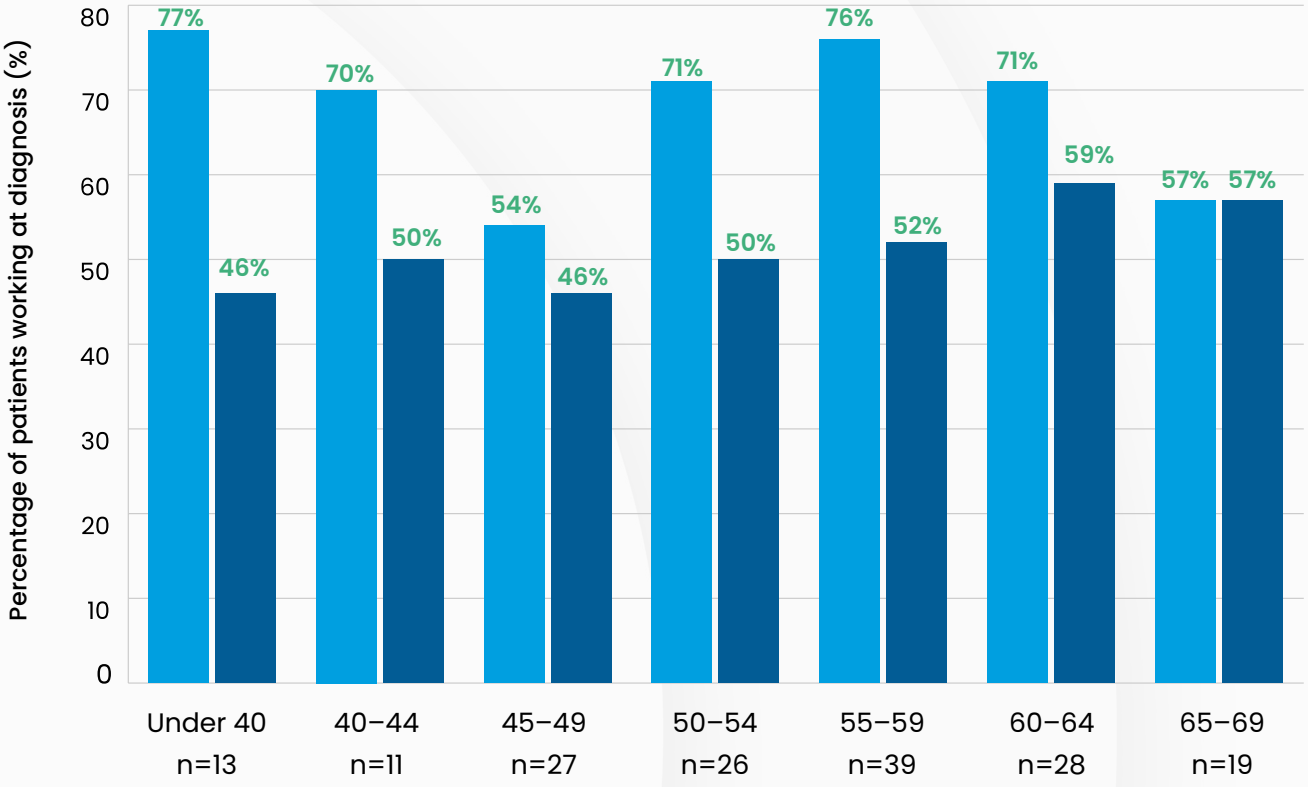


Figure 10. Employment impact of diagnosis by age group.

Teal (numbers): % working at diagnosis (of all respondents in that age group). Light blue: % who reduced hours after diagnosis (of those working). Dark blue: % who stopped working after diagnosis (of those working). Patients aged 70+ (n=17) were all not working at diagnosis and are excluded. Age group 35–39 has n=2; interpret with caution.



"Under 40" combines age bands 25–29, 30–34 and 35–39 (n=13, all working diagnosis). Patients aged 70+ were all not working at diagnosis and were excluded. Percentages are of those working at diagnosis.

Reduced hours after diagnosis

Stopped working after diagnosis

Employment impact by sex

Table 1. Comparison of men and women who reduced hours or stopped working

Employment outcome	Women (%)	Men (%)
Continued working without reducing hours	19.6	23.9
Reduced hours	57.9	58.7
Stopped working	22.4	17.4
Total	**100**	**100**

There was little difference between the proportion of men and women who reduced their hours or stopped working.

Table 2. Reduction in hours and stopped working by age group

Age at diagnosis	Reduced hours (n=89)	Percentage of reduced-hours group	Stopped working (n=32)	Percentage of stopped-working group
25–29	3	3.4%	1	3.1%
30–34	6	6.7%	1	3.1%
35–39	1	1.1%	1	3.1%
40–44	7	7.9%	2	6.3%
45–49	14	15.7%	12	37.5%
50–54	17	19.1%	4	12.5%
55–59	25	28.1%	7	21.9%
60–64	12	13.5%	3	9.4%
65–69	4	4.5%	1	3.1%
≥70	0	0.0%	0	0.0%
Total	**89**	**100.0%**	**32**	**100.0%**

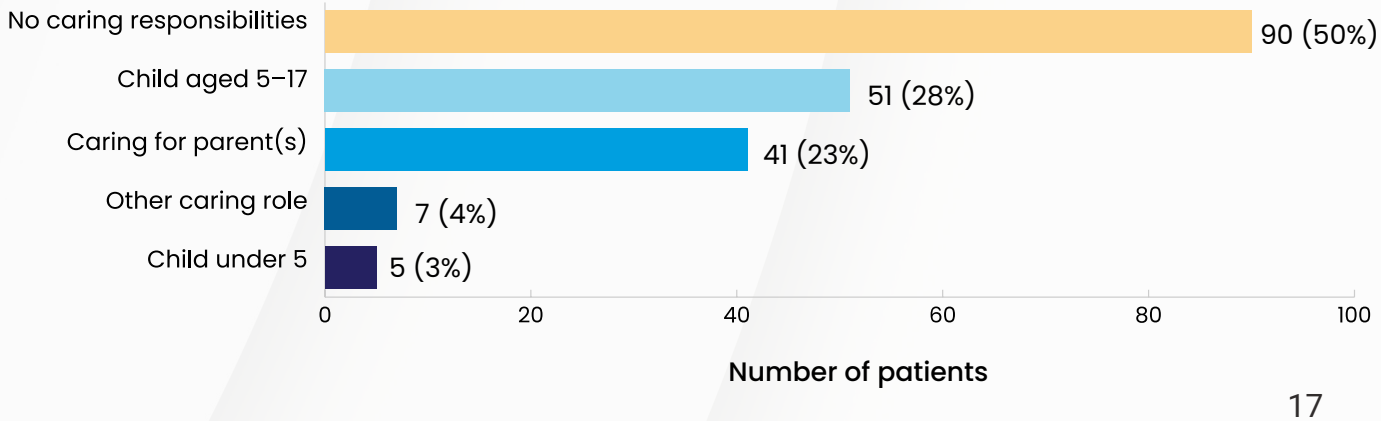
Employment disruption was concentrated among respondents diagnosed between 45 and 59 years of age. Among those who reduced their hours, the largest proportion (28.1%) were diagnosed at 55–59 years, whereas among those who stopped working completely, the highest proportion (37.5%) were diagnosed at 45–49 years. However, because of the relatively small number of respondents who stopped working, this figure would have a low level of confidence.

Nearly two-thirds of both groups were diagnosed between 45 and 59 years, highlighting the substantial impact of ALK-positive NSCLC on employment during peak working years.

13. Caring responsibilities

Half of respondents (90/180, 50%) reported having caring obligations: 51 patients (28%) were caring for a child aged 5–17, and 41 (23%) were caring for one or more parents. Five patients (3%) had a child under the age of five. These findings highlight the dual burden faced by many patients: managing a serious cancer diagnosis while simultaneously providing care to dependants.

Figure 11. Caring responsibilities at time of diagnosis (n=180; multiple responses permitted)



14. Pre-existing conditions

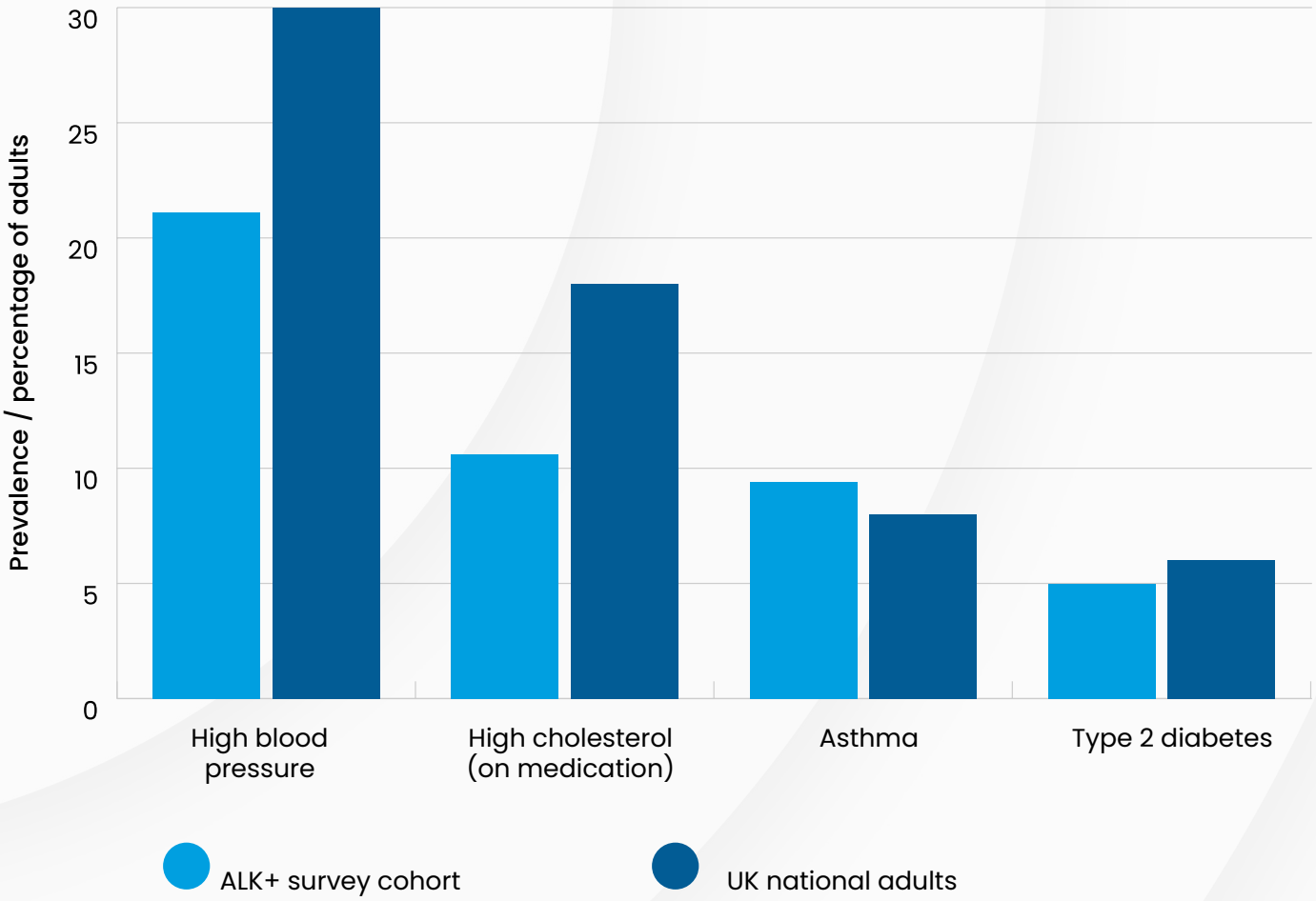
This section compares the prevalence of pre-existing conditions reported by survey respondents against published national prevalence figures for the UK adult population. The purpose is to determine whether patients with ALK-positive NSCLC carry a comorbidity burden that is higher, lower, or broadly comparable to the general population.

The survey asked: “Before diagnosis, was the patient taking medication for any of the following conditions?” The use of the phrase taking medication is important — it captures only conditions that were clinically identified and treated, not undiagnosed disease. National comparators have been selected on the same basis where possible, using treated or diagnosed prevalence rather than raw measured rates.

The majority (101/180, 56%) reported no pre-existing conditions requiring medication. Among those with conditions, high blood pressure was the most prevalent (38 patients, 21%), followed by high cholesterol (19, 11%), asthma (17, 9%), and type 2 diabetes (9, 5%).

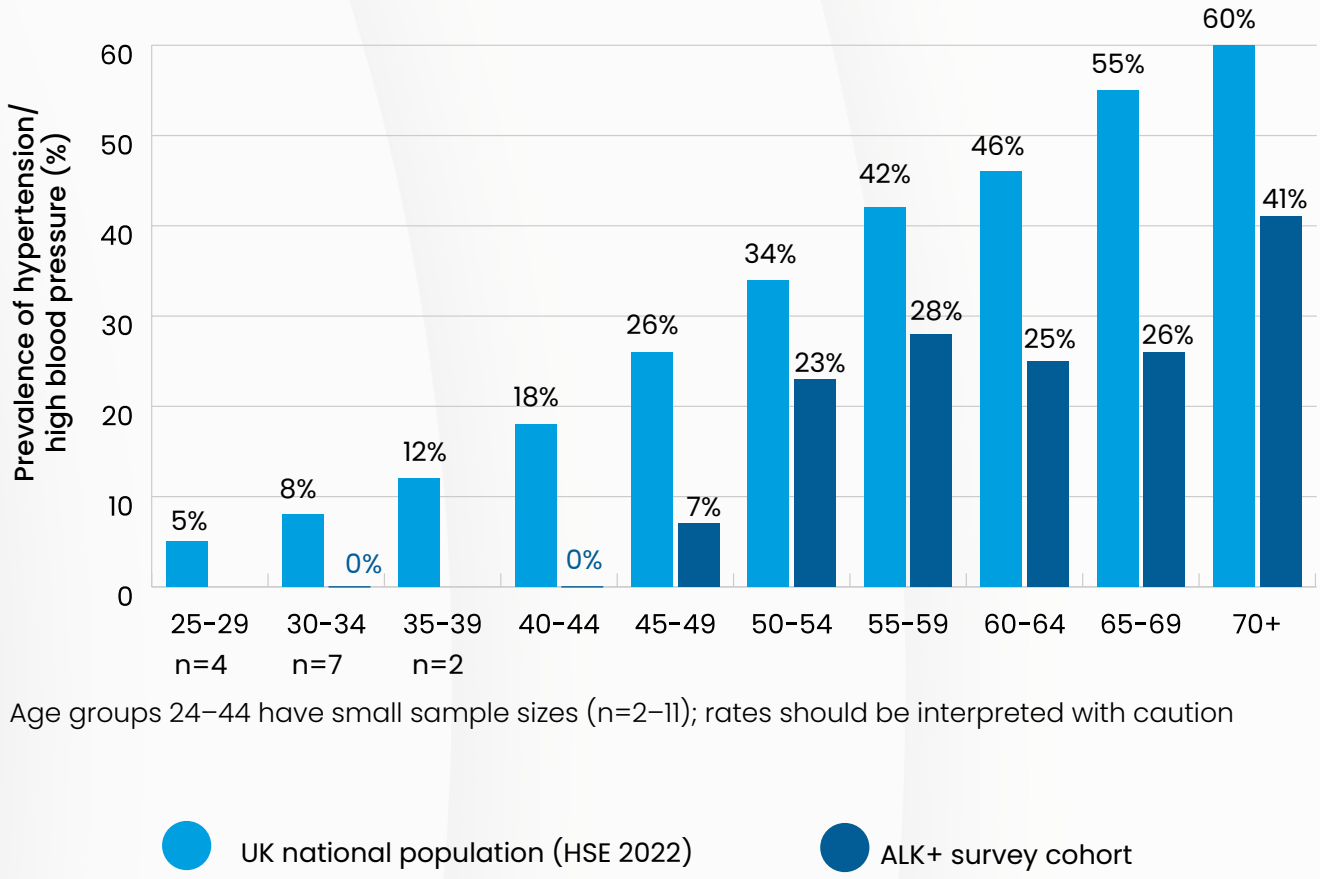
The respondents had a median age of 57 years, considerably older than the general UK adult population (median about 40 years). Comorbidities such as hypertension and high cholesterol rise steeply with age; direct comparison with all-age national figures will therefore tend to understate the deficit in this cohort. Age-adjusted interpretation is provided throughout.

Figure 12. Prevalence of pre-existing conditions: ALK+ survey cohort (dark blue) vs UK national adult population (light blue). Survey question captured conditions requiring medication only.



The following figures compare age-related rates of high blood pressure and high cholesterol against the most appropriate national comparator. Because of the small numbers in each age groups, charts for asthma and diabetes type 2 have not been produced.

Figure 13. Hypertension by age group: UK national population (HSE 2022 light blue) vs ALK+ survey cohort (dark blue). ALK+ rates are consistently below national figures at every age band. Groups aged 25–44 have small cohort sample sizes (n=2–11) and should be interpreted with caution.



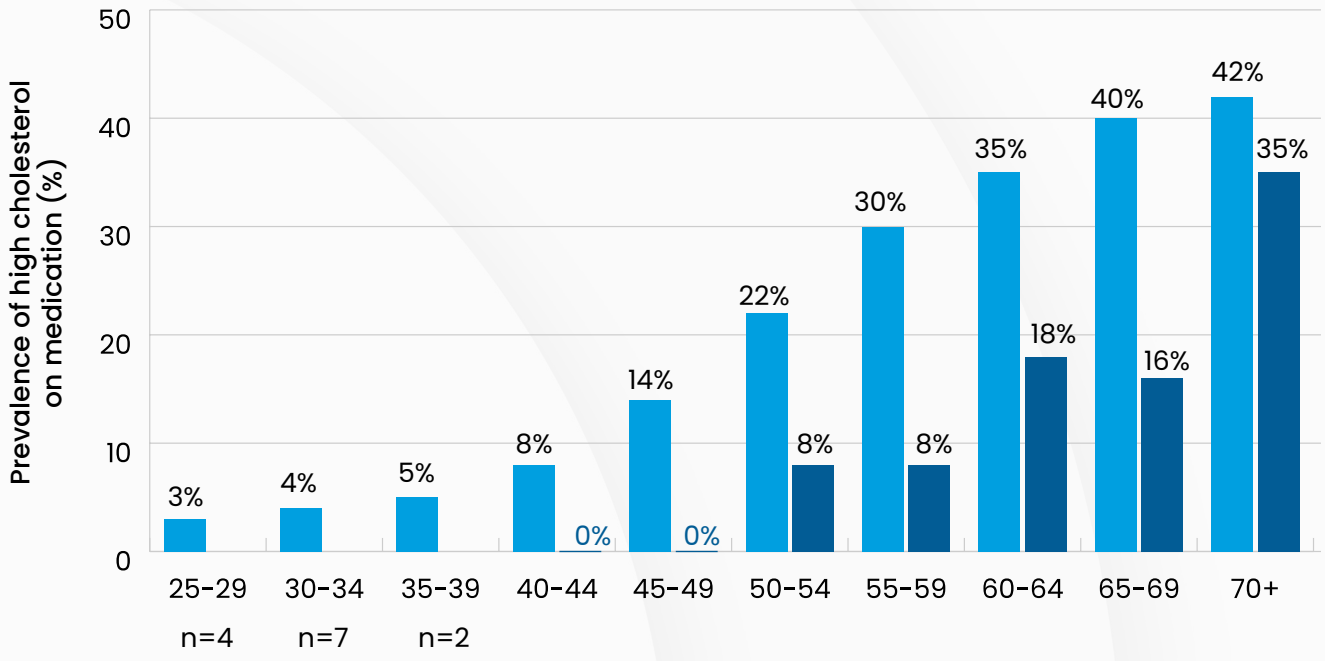
Age groups 24–44 have small sample sizes (n=2–11); rates should be interpreted with caution

Survey cohort: 38 of 180 respondents (21.1%) were taking medication for high blood pressure before their cancer diagnosis.

National comparator: The Health Survey for England (HSE) 2022 [3] found that 30% of UK adults have hypertension (measured BP ≥140/90 mmHg or on antihypertensive medication), with approximately 21–22% of all adults on medication. The ONS (2021) estimated 32% of English adults had hypertension, with 29% undiagnosed [4], [5].

Interpretation: the ALK+ cohort rate is lower than the national figure at every age band. In the 55–59 and 60–64 groups — which contain the most respondents — cohort rates are 28% and 25% respectively, against national figures of about 42% and about 46%. Even in the 70+ group, 41% of ALK+ respondents had hypertension versus about 60% nationally. An age-adjusted expectation for this cohort would be approximately 38–42%; the observed rate of 21% is therefore roughly half the age-expected figure, consistent with the healthy, never-smoker demographic of this patient population.

Figure 14. High cholesterol (on lipid-lowering medication) by age group: UK national population (light blue, estimated from HSE 2021 [3] and NHS prescribing data) vs ALK+ survey cohort (dark blue). No ALK+ respondents aged under 50 reported treated high cholesterol.



Age groups 25–49 have small to very small ALK+ sample sizes (n=2–27 with 0 cases); interpret with caution. National "on medication" rates are estimated from HSE 2021 measured cholesterol data and NHS statin prescribing patterns.

UK national population on lipid-lowering medication (HSE 2021; NHS prescribing data)

ALK+ survey cohort

Survey cohort: 19 of 180 respondents (10.6%) were taking medication for high cholesterol before diagnosis.

National comparator: The HSE 2021 [3] found 59% of UK adults had raised total cholesterol (≥5 mmol/L), highest in the 45–64 age group (72%). On medication, NHS prescribing data indicate approximately 18–20% of UK adults are on lipid-lowering medication (statins) [6], [7].

Interpretation: As shown in **Figure 14**, no ALK+ respondent aged under 50 was taking medication for high cholesterol. In the 50–54 and 55–59 groups (combined n=65) the cohort rate is 8%, compared with national estimates of about 22% and about 30% respectively. The 60–64 group shows 18% versus about 35% nationally. The overall cohort rate of 10.6% is materially lower than the about 18–20% national rate. Small sample sizes in several bands require cautious interpretation, but the direction is consistent throughout.

Asthma

Survey cohort: 17 of 180 respondents (9.4%) were taking medication for asthma before diagnosis.

National comparator: DHSC data (cited in the House of Commons Library, 2025) [8] estimated 3,886,879 people over the age of six in England had diagnosed asthma in 2023/24, equating to 6.5% of the total population. Adult-only rates are higher, at approximately 8–9% (Asthma UK).

Interpretation: The cohort rate of 9.4% is broadly in line with the adult asthma prevalence of 8–9%. This is the one condition where the ALK+ cohort does not show a marked deficit relative to national figures. The slight elevation over the all-age figure is expected given the cohort's age profile and female majority (61%), since women have higher asthma rates than men.

Type 2 Diabetes

Because of the low number, a detailed analysis of the incidence of Type 2 Diabetes has not been carried out.

Absence of specified pre-existing conditions

The relatively low proportion of respondents who reported having at least one of the specified pre-existing conditions reinforces the picture of ALK-positive NSCLC as a disease affecting a population that is, in many respects, metabolically and cardiovascular healthier than the general population of similar age. The dominant risk factor profile — younger age, female sex, never-smoker status, low cardiovascular comorbidity — is now well recognised in the clinical literature and is clearly reflected in this survey.

Limitations

Self-reported data
All survey data are self-reported and have not been verified against medical records. Recall bias may affect responses, particularly regarding pre-diagnosis conditions.

Medication criterion
The survey asked only about conditions requiring medication. This will undercount conditions managed by lifestyle alone.

Age structure
The cohort skews older (median 57) than the UK adult population (median about 40). Age-specific national comparators would be more precise; these are not uniformly available across all conditions.

Sample size
With 180 respondents, confidence intervals are wide. For rare conditions such as type 2 diabetes (n=9), small changes in classification could materially shift percentages.

Representativeness
The survey was distributed via ALK Positive UK's membership and social media channels; it may not be fully representative of all UK ALK-positive NSCLC patients.

15. Conclusions

Distinct patient profile, profane consequences

The 2025 ALK Positive UK Patient Survey confirms and deepens what is increasingly well established in the clinical literature: ALK-positive NSCLC is a disease with a strikingly distinct patient profile, and that profile has profound human consequences.

Severe economic impact, lives interrupted

The findings tell a clear story. The typical ALK-positive patient represented in this survey is a woman in her mid-to-late fifties, diagnosed at stage 4, who had never smoked or had only a minimal smoking history. She was likely to be working at the time of diagnosis and, in more than half of cases, was also providing care to a child or parent. The economic impact is severe: more than two-thirds of those who were working reduced their hours as a result of their diagnosis, and one in two stopped working altogether. These are not merely clinical statistics — they describe lives substantially disrupted at a time when many patients had every reason to expect decades of good health ahead of them.

ALK-positive NSCLC can strike the healthy

Despite being considerably older on average than the general UK adult population, ALK-positive respondents in this survey reported comorbidity rates that were broadly comparable to — or materially lower than — national figures across hypertension, high cholesterol, and type 2 diabetes. The most striking finding is hypertension: in a cohort with a median age of 57, where an age-adjusted rate of 38–42% would be expected, only 21% of respondents were taking antihypertensive medication. More than half the cohort reported no pre-existing conditions requiring medication at all. This reinforces the established picture of ALK-positive NSCLC as a disease that can and does strike people who are, by most conventional measures, healthy.

Lung cancer can strike beyond the usual risk profile

That paradox — a healthy population carrying a serious cancer — has practical implications. Public awareness campaigns anchored in smoking as the primary risk factor for lung cancer will not reach these patients. Symptom attribution is more likely to be delayed when individuals do not see themselves as belonging to a high-risk group. Earlier diagnosis, which remains the single most powerful tool for improving survival, depends on reaching people who do not expect to be ill.

Turning data into action for ALK-positive patients

ALK Positive UK will continue to use data such as these to advocate for improved awareness, faster diagnostic pathways, and equitable access to targeted therapies.

Surveys of this kind are only possible because patients and carers choose to contribute their experiences. That generosity of spirit, expressed by 180 individuals across the UK and Ireland, is what makes evidence-based patient advocacy possible — and it is what drives this charity's work.

16. References

[1] J. L. Schneider, J. J. Lin, and A. T. Shaw, "ALK- Positive Lung Cancer: A Moving Target," Nature Cancer 4 (2023): 330–343.

[2] Lung cancer - Causes - NHS Evaluating Diagnostic and Treatment Timelines for ALK-Positive NSCLC Patients: Results from a Global Registry - Science Direct

[3]. Available at: https://www.natcan.org.uk/wp-content/uploads/2026/02/NLCA-State-of-the-Nation-Report-2026.pdf?utm_source=chatgpt.com

[4]. Available at: https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/demographics/age-groups/latest/?utm

[5] NHS England Digital (2024). Health Survey for England 2022, Part 2: Adult Health. NHS England Digital. Published 24 September 2024. Available at: https://digital.nhs.uk/data-and-information/publications/statistical/health6survey-for-england/2022-part-2/adult-health [Accessed: June 2025]

[6] Office for National Statistics (ONS) (2021). Risk factors for undiagnosed high blood pressure in England: 2015 to 2019. ONS Statistical Bulletin. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/articles/riskfactorsforundiagnosedhighbloodpressureinengland/2015to2019 [Accessed: June 2025]

[7] NICE (2019). Hypertension in adults: diagnosis and management (Guideline NG136). NICE. Published August 2019. Available at: https://www.nice.org.uk/guidance/ng136/chapter/Context [Accessed: June 2025]

[8] NHS England Digital (2023). Health Survey for England 2021, Part 2: Adult Health — Cholesterol. NHS England Digital. Published 16 May 2023. Available at: https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england/2021-part-2/adult-health-cholesterol [Accessed: June 2025]

[9] Our Future Health (2023). Over half of people found to have high cholesterol and over 1 in 4 found to have high blood pressure. Our Future Health Programme. Published July 2023. Available at: https://ourfuturehealth.org.uk/news/over-half-of-people-found-to-have-high-cholesterol-and-over-1-in-4-found-to-have-high-blood-pressure-in-transformative-health-research-programme/ [Accessed: June 2025]

[10] House of Commons Library (2025). World Asthma Day (Research Briefing CDP-2025-0104). UK Parliament. Published 23 April 2025. Available at: https://commonslibrary.parliament.uk/research-briefings/cdp-2025-0104/ [Accessed: June 2025]

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