ALK Positive Lung Cancer (UK)

Privacy policy

We want everyone who supports us, comes to us for support or contacts us to feel confident and comfortable with how we look after their personal information.

Where we ask you to provide us with any information by which you can be identified, you can be assured that it will only be used in accordance with this privacy statement, and in line with UK data protection law which includes but may not be limited to the Data Protection Act 2018, the UK General Data Protection Regulations (UK GDPR) and the Privacy and Electronic Communications Regulation (PECR).

This Privacy Policy explains how we collect, use and store personal information. Personal information means any information that could identify you.

The ALK Positive UK Privacy Policy may change, so please check from time to time. This version was updated on 12 February 2026.

1. Who we are

We are ALK Positive Lung Cancer (UK), a registered charity in England and Scotland. We are committed to protecting your personal information and making every effort to ensure that your personal information is processed in a fair, open and transparent manner.

We are a "data controller" for the purposes of the Data Protection Act 2018 and the UK General Data Protection Regulation ("Data Protection Law"). This means that we are responsible for the processing of your personal information.

2. How we collect information about you.

We collect information from you when you:

a. Register for the Support Group
b. Register for The ALK Register
c. Use our website
d. Contact us using the website
e. Contact us by email
f. Contact us by post

g. Book a place at one of our events
h. Make a donation to our bank account
i. Fundraising using a fundraising platform, such a Just Giving and Enthuse.
j. Purchase something from the online shop
k. Complete a survey form
l. Provide photographs
m. Provide personal stories

3. Information we collect and how we use it.

The personal information we collect about you will be used anonymously to advance the Charity's aims of supporting and empowering patients, advocating nationally for best practice, campaigning for early diagnosis and raising the awareness of lung cancer amongst non-smokers.

We collect personal information when you -

i. Register with the Support Group or The ALK Register –

a. your name
b. email address
c. postal address
d. telephone number
e. date of diagnosis
f. stage at diagnosis
g. age at diagnosis
h. hospital where treated

We use your contact information to communicate with you about events, activities, charity news, ALK-positive news, to send a Newsletter and to invite you to take part in surveys. We use information about your diagnosis anonymously for the purpose of advocating and campaigning for best practice and early diagnosis.

ii. Visit the website

We collect information on your website usage using tracking software - pages visited, IP address, browser, location and device used.

iii. Contact us using the website -

a. Name
b. Telephone number
c. Email address
d. Contents of the message

We use your contact information to communicate with you.

iv. Contact us by email -

a. Name
b. Email address
c. Contents of the email

We use your contact information to communicate with you.

v. Contact us by post -

a. Name
b. Address
c. Contents of the letter

We use your contact information to communicate with you.

vi. Book a place at an event -

a. Name
b. Address
c. Telephone number
d. Email address

We use your contact information to communicate with you.

vii. Make a donation to our bank account -

a. Name
b. Account number
c. Sort number

We use your contact information to communicate with you, to make Gift Aid claims and to comply with the Charities (Protection and Social Investment) Act 2016 and follow the recommendations of the official regulator of charities, the Charity Commission, which require us to identify and verify the identity of supporters who make major gifts so we can assess any risks associated with accepting their donations.

viii. Fundraise, using a platform such as Just Giving and Enthuse -

a. Name

We use your name to record the amount raised.

ix. Make a purchase from our online shop -

a. Name
b. Address
c. Email address
d. Telephone number

We use your contact information to communicate with you and to provide the items purchased.

x. Completing a Survey Form -

a. Name
b. email address
c. Information provided in the survey

We use your contact information to communicate with you. We use the information you provide in the survey about your diagnosis, treatment and care anonymously for the purpose of advocating and campaigning for best practice and early diagnosis.

xi. Photographs

We take photographs at events, including the conference and regional lunches, invite fundraisers to provide photographs, invite members to provide photographs for campaigns and for social media and we use photographs posted on the charity's Facebook Support Group. We obtain the consent of members before using any of their photographs for publicity purposes.

xii. Personal Stories

We invite members to provide their personal stories and obtain their consent to using the stories on the website, in Newsletters, social media and for publicity purposes.

4.` Sensitive Personal Information

Data Protection Law recognises that some categories of personal information are more sensitive. Sensitive Personal Information can include information about a person's health, race, ethnic origin, political opinions, sex life, sexual orientation or religious beliefs. We do collect information about a person's health and we use this information anonymised to advance the charity's objectives. We do not collect any other sensitive personal information.

5. Sharing your information

The personal information we collect about you will be used to advance the Charity's aims of supporting and empowering patients, advocating nationally for best practice,

campaigning for early diagnosis and raising the awareness of lung cancer amongst non-smokers.

Personal Information is stored on a cloud-based platform that is available to the Chair, Secretary, Treasurer, Chief Executive Officer, Charity Manager and Administrative Assistant.

We also use the following 3rd party organisations to store personal information–

a. Survey Monkey – membership questionnaires and surveys
b. Mail Chimp – emails to members
c. Xero – accountancy system
d. Google Share – storage of personal information
e. Zee Maps – location of members

The information stored on these platforms is accessed by designated trustees and staff.

These platforms are hosted in the USA, so the information you provide to us is initially stored there. The contract we have with these providers ensures their practices comply with UK data protection law and we regularly delete data from this system.

We never provide any identifiable personal information to researchers, pharmaceutical companies and other organisations and individuals. We do provide anonymised data to advance the charity's objectives.

6. Legal disclosure

We may disclose your information if required to do so by law (for example, to comply with applicable laws, regulations and codes of practice or in response to a valid request from a competent authority.

7. Keeping your information safe

We take looking after your information very seriously. We've implemented appropriate physical, technical and organisational measures to protect the personal information we have under our control, both on and off-line, from improper access, use, alteration, destruction and loss.

Our website contains links to other sites. While we try to link only to sites that share our high standards and respect for privacy, we are not responsible for the content, or the privacy practices employed by other sites.

8. How long we hold your information for

We only keep it as long as is reasonable and necessary for the relevant activity, which may be to fulfil statutory obligations (for example, the collection of Gift Aid).

Information provided for a specific event will be deleted after the event.

Some personal information, eg age at diagnosis, will be retained indefinitely as it remains relevant to our advocacy and campaigning work.

9. Your rights

You have various rights in respect of the personal information we hold about you – these are set out in more detail below. If you wish to exercise any of these rights or make a complaint, you can do so by contacting us using the website, email to hello@alkpositive.org.uk, telephoning 07975623515 or writing to the registered office of the charity (see website and Charity Commission).

You can also make a complaint to the data protection supervisory authority, the Information Commissioner's Office, https://ico.org.uk/

a. Access to your personal information: You have the right to request access to a copy of the personal information that we hold about you, along with information on what personal information we use, why we use it, who we share it with, how long we keep it for and whether it has been used for any automated decision making. You can make a request for access free of charge. Please make all requests for access in writing and provide us with evidence of your identity.

b. Right to object: You can object to our processing of your personal information where we are relying on a legitimate interest (or those of a third party) and there is something about your particular situation which makes you want to object to processing on this ground. You also have the right to object where we are processing your personal information for direct marketing purposes. Please contact us as noted above, providing details of your objection.

c. Consent: If you have given us your consent to use personal information (for example, for marketing), you can withdraw your consent at any time.

d. Rectification: You can ask us to change or complete any inaccurate or incomplete personal information held about you.

e. Erasure: You can ask us to delete your personal information where it is no longer necessary for us to use it, or you have withdrawn consent, or where we have no lawful basis for keeping it.

f. Portability: You can ask us to provide you or a third party with some of the personal information that we hold about you in a structured, commonly used, electronic form, so it can be easily transferred.

g. Restriction: You can ask us to restrict the personal information we use about you where you have asked for it to be erased or where you have objected to our use of it.

h. No automated decision making: Automated decision-making takes place when an electronic system uses personal information to make a decision without human intervention. You have the right not to be subject to automated decisions that will create legal effects or have a similar significant impact on you, unless you have given us your consent, it is necessary for a contract between you and us or is otherwise permitted by law. You also have certain rights to challenge decisions made about you. We do not currently carry out any automated decision-making.

Please note, some of these rights only apply in certain circumstances and, where one of your rights does not apply, we will communicate the reason to you.