ELF strategy 2026-2029

Our mission: In partnership with the European Respiratory Society, the European Lung Foundation brings patients and the public together with healthcare professionals to improve lung health and advance prevention, diagnosis, treatment and care.

Our vision: People living with lung conditions are at the centre of lung healthcare, research and policy. Everyone has access to clear, reliable information they can trust about lung health and disease in their own language.

ELF is:

- A community where people living with lung disease are empowered to lead change
- A platform where patients shape the conversations, priorities and solutions that affect them
- A collective voice ensuring that lived experience is heard in healthcare, research and policy

How we will work

Across all our strategic pillars, we will apply the following principles:

- **Patient leadership:** Patients will shape our priorities, activities and decisions.
- **Inclusion and equity:** We will reach and meaningfully involve diverse and underserved communities.
- **Partnership**: We will work with patients, healthcare professionals and organisations as equal partners to co-create solutions and achieve greater impact.
- **Innovation:** We will responsibly embrace new approaches, digital technologies and AI to improve access, engagement, education and participation.
- **Communicating and demonstrating impact:** We will demonstrate the difference ELF makes through evidence, experiences and meaningful outcomes.
- **Evidence-led:** All our work will be grounded in independent, high-quality evidence.

Overview


Be patient-driven and community-focused
Increase knowledge and understanding, and support self-management
ELF Strategy 2026-2029
Build impactful and valuable partnerships
Have a strong voice to drive change

Strategic pillar 1: Be patient-driven and community-focused

Overall objective: Build a connected and diverse ELF community where patients, carers, family members and patient organisations feel like they belong.

Goal	What we will do
Support and strengthen the ELF community	• Ensure that individuals and organisations feel that they are "part" of the ELF community. • Investigate what ELF individual "membership" could look like – especially in relation to ERS membership. • Strategically develop PAGs where there are gaps and requests (e.g. PCD, paediatric, TB). • Create clear, accessible pathways for patient involvement to empower patients to find their route to influence within the organisation and the broader ERS ecosystem. • Review the benefits and expectations of membership of the patient organisation network. • Strengthen relationships between patient organisations and encourage active participation across the network, specifically from Eastern Europe.
Increase engagement and participation	• Develop targeted campaign with ERS to reach the patients of their members. • Continue to develop ELF Connect as a platform that enables connection, participation and peer support across the community. • Further strengthen ELF presence of leadership on social media and drive connections. • Develop specific outreach strategies for different communities and groups. • Strengthen patient engagement capacity across countries where patient organisations are underdeveloped or patient involvement remains limited. • Provide structured training, leadership development, mentoring and practical support to local patient leaders, enabling them to build sustainable organisations, represent patients effectively and participate meaningfully in healthcare, research and policy decisions.
Amplify patient voices	• Ensure that we can amplify the voices and views we have collected and have a strong organisational memory and position. • Consider new ways to amplify voices, e.g. pro-active press work to offer quotes and comments or more support for our patient leaders on social media platforms. • Optimise and build Global Voices as a way to collect patients' views and share with Congress delegates and beyond.
Promote inclusion	• Test out new ways of amplifying the voices of underserved communities. • Invest time in training on different approaches and cultural awareness. • Equip our diverse members to communicate effectively. • Encourage people to run community fundraising to support delivery of relevant activities. • Use Healthy Lungs for Life and IRC to drive the profile of ELF and recruit supporters. • Address inequalities in access to lung health – prevention, diagnosis, treatment, care, research and reliable information.

Goal	What we will do
Develop leaders	• Offer a range of clear pathways to ELF leadership. • Offer training to leadership. • Establish a structured ELF mentoring and peer-support programme connecting experienced patient advocates and organisations with emerging patient leaders from countries with limited patient engagement.
Communicate the ELF identity clearly	• Ensure ELF values are well communicated and clear to community and wider public. • Promote the unique selling points of ELF and ensure they are well communicated and understood. • Produce an annual impact report to highlight how we have lived out our values over the year.
Empower young people	• Invest in HLfL4schools - rolling out in as many countries as possible. • Strengthen and develop the youth group – finding novel ways to engage and gather opinions of young people. • Empower young people from diverse backgrounds for whom their English is not strong to still be involved in ELF activities closer to home. • Facilitate young people having a stronger voice representing issues important to them, e.g. tobacco and climate change. Maximising opportunities both local and global, e.g. local parliament/MPs as well as EU parliament and ERS.

Strategic pillar 2: Increase knowledge and understanding, and support self-management

Overall objective: Enable people living with lung conditions to access trusted information, understand research and develop the knowledge, skills and confidence to manage their health.

Goal	What we will do
Expand patient learning opportunities	• Pilot and develop the concept of an ELF patient conference linked to the ERS Congress, developing content and concepts together with patient organisations. • Further grow ELF's offering of online patient conferences – strategically linking them to ERS small meetings and events. • Provide free registration online to patient orgs and patients active on ELF committees to all ERS events.
Strengthen patient participation in science and education	• Do audit on our activities – time taken and where we add value. • Continue to maximise the value and impact that patient representatives can bring to the ERS Congress as Chairs and speakers, and in sessions such as studio sessions. • Involve patients more systematically in the smaller topic-specific conferences: e.g. sleep, CF, etc. • Provide resource and ensure timely processes to support patient input into key ERS publications: e.g. ERM chapters. • Support patient participation in guidelines, publications and educational initiatives. • Explore opportunities for patient editors and reviewers in ERS publications.

	• Strategically increase ELF participation and leadership via Lungs Europe in EU projects, and increase opportunities for patient org network partners and PAG members. • Ensure patient input into advocating for lung health funding at national and European level. • Have a strong voice in countering misinformation. • Promote patient-centred outcomes and quality of life as essential components of healthcare. • Strengthen patient involvement across the research lifecycle, from identifying research priorities and designing studies to interpreting results and supporting implementation
Improve access to evidence and research	• Continue to develop co-designed evidence-based educational materials. • Work with ERS publications to ensure that access to lay summaries of ERS articles is maximised (e.g. using AI, video discussion). • Ensure lay guidelines and videos are produced in as many languages as possible and improve dissemination. • More systematic reporting on key ERS events – such as topic-specific conferences and Congress, including latest takeaways etc. • Explore responsible and inclusive use of digital technologies and artificial intelligence to improve access to information, education, self-management and patient participation.
Develop patient training and self-management programmes	• Further strengthen and promote the European Patient Ambassador Programme (EPAP). • Expand EPAP content and learning modules. • Explore opportunities for institutional funding for EPAP. • Look into opportunities to provide face to face independent training for patient representatives – skills based training. • Develop ambassadors as peer-to-peer support.
Inspire the public to care for their lung health	• Develop the Healthy Lungs for Life campaign further – optimising opportunities in the different theme areas (e.g. vaccination, air quality, smoking/vaping). • Connect with other NCD areas to optimise impact and share messaging. • Stronger presence of Healthy Lungs for Life on social media. • Partner with national organisations and work with national authorities to drive the use of the occupational tool. • Actions to reduce stigma of lung disease • Inspiring governmental change

Strategic pillar 3: Build impactful and valuable partnerships

Overall objective: Build strong and effective partnerships that bring together patients, healthcare professionals, organisations and supporters to improve lung health and drive meaningful change.

Goal	**What we will do**

Strengthen the ELF-ERS partnership	• Continue to foster the unique and powerful partnership of ELF and ERS – professionals and patients working in partnership at the highest level. • Strategically involve more patients in CRCs with a mandatory spend for patient activities (5% of budget). • Pilot patient engagement in ERS Assemblies (e.g. sleep and paediatrics via APEC). • Use the ELF Council meeting to develop the relationship between ERS and ELF leadership. • Review ELF presence on all ERS committees. • Consistent ELF presence and contribution to high-level ERS events (e.g. ERS Summit).
Strengthen strategic partnerships and collaborations	• Co-lead the IRC – actively supporting the involvement and engagement of patient organisations in national coalitions. • Develop Healthy Lungs for Life partnerships at local (city), national and global levels and integrate into other initiatives (e.g. IRC, fundraising). • Work with international organisations, including WHO, to advance shared lung health priorities (e.g. Lung Health Resolution). • Being a respected patients voice for EU policy consultations and processes. • Work in partnership with the ERN-LUNG on rare respiratory disease – specifically supporting equal access to expert centres for patients with rare lung diseases. • Develop practical tools and resources for patient organisations, including guidance on advocacy, organisational development, fundraising, communication, participation in research and engagement with healthcare professionals and policymakers.
Grow support and be sustainable	• Engage and steward foundations, trusts and high-value individuals (develop the concept of an ELF event (e.g. dinner as a fundraiser during the ERS congress). • Develop fundraising strategy in alignment with national activities (IRC, HLfL etc.). • Sustain the work of EU projects through network building, information sharing. • Developing EU proposals and increasing application capacity in partnership with Lungs Europe to enable key topics and intiatives to be funded. • Share impact report with high-value organisations and individuals to evidence our reach to encourage fundraising.

Strategic pillar 4: Have a strong voice to drive change

Overall objective: Ensure the voices and priorities of people living with lung conditions influence policy, research and decision-making at local, national and international levels.

Goal	**What we will do**
Strengthen patient-informed advocacy	• Work in partnership with ERS Advocacy to ensure patient perspectives inform position papers, consultations and advocacy activities where appropriate. • Ensure advocacy priorities reflect the needs and experiences of patients, patient organisations and the wider public.

	• Align advocacy activities with shared priorities across ELF and ERS. • Ensure that we are working on the policy project cycle, focussed on the priorities of healthcare professionals (ERS) and patients and the public (ELF). • Be the patient leader in advocacy. • Mature patient involvement in advocacy from emotional scene setting to equal contributions to solutions. • Create opportunities for meaningful patient participation at European level for representatives from countries with limited patient engagement, ensuring that geographical and organisational inequalities do not prevent patients from having a voice in ELF activities and European decision-making.
Increase patient influence in policy and decision-making	• Support patients to confidently share their experiences and perspectives in policy and public settings. • Create opportunities for patients and patient organisations to contribute to policy discussions and decision-making processes. • Strengthen patient involvement in relevant working groups and advisory structures. • Ensure that patients and public understand the policy actions needed to improve lung health. • Robust recording of patient views and experiences to ensure policy input is representative of wider patients/public.
Strengthen policy partnerships and networks	• Work with ERS to strengthen the MEP Lung Health Group. • Build and maintain relationships that help advance lung health priorities and patient-centred policies. • Support the development of national and supranational lung health plans via involvement in the IRC.
Raise the profile and influence of ELF	• Consider a patron or ambassador for ELF – who has commitment to lung health and will help with visibility and reach. • Look at positioning Lungs Europe as a leader in lung health philanthropy via the development of a Lung health fund.