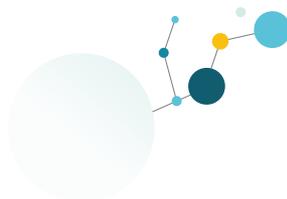


EUROPEAN LUNG HEALTH GROUP



TOWARDS A BREATHE VISION FOR 2030



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Written by Neil Fitch.

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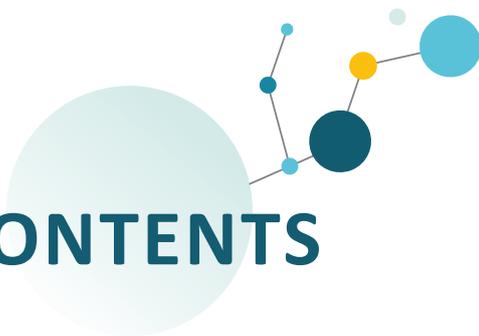
This publication would not have been possible without the insights, vision and dedication of the eight European organisations that have participated in the discussions and drafting of this paper, on a voluntary basis:

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For more acknowledgements and information on this project visit www.breathevision.eu





CONTENTS

1. A Breathe Vision for change	4
2. Introduction	6
3. Breathe Vision for 2030	8
3.1. Raising awareness of respiratory disease	8
3.2. Greater prevention of lung disease.....	10
3.3 Getting the right care	12
3.4. Advancing research into lung health.....	14
3.5. Addressing COVID-19 threats and seizing the opportunities	16
4. Building a vision for the future of respiratory health	17
5. A vision for respiratory health in 2030	18
Acknowledgment	20
Glossary	21
Endnote references	22





1. A BREATHE VISION FOR CHANGE

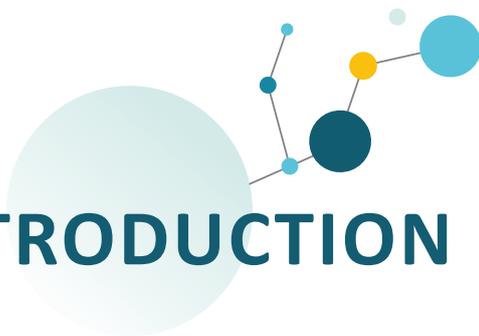
This paper aims to create a Breathe Vision for 2030, outlining the changes that lung patients want to see in their lives. The importance of these changes is reflected in the impact that lung health has on our general health. Lung health, particularly in children, is such an important factor in our current health and in predicting our future health that attention for healthy lungs is crucial in improving the overall wellbeing of our population.

Respiratory disease is hard on people's bodies. It does not just affect the lung, but how you are able to live. The choices that patients make have affects on the whole of society, from how active your life is to your ability to work. The changes that lung patients want to see are fundamental and are reflected in the UN Sustainable Development Goals (SDGs). This is especially true for SDG 3 on good health and well-being, SDG 10 on reduced inequality and SDG 13 on climate action, given the related impact on air quality. Our vision focuses on the changes we want to see within five topics:

Awareness: By 2030 we should see a deeper understanding of how information affects health. This should lead to co-decisions being made between patients, health care professionals, policy-makers and other stakeholders and on all health policies. A compassionate response would support current calls for greater health quality in Europe and for a European Health Union.

Prevention: The window of opportunity afforded by COVID-19 needs to be leveraged to draw more attention to preventing lung disease. Prevention measures would help Europe achieve its international commitments and goals. A vision to reduce air pollution and to tackle the climate change emergency from a European level will make it possible for people to make healthy choices. Equally, education should support greater self-awareness of the consequences of individual actions. Our vision sees lung health needs leading pioneering policies to address the environment, behaviour and air quality risk factors responsible for much of the respiratory disease in Europe.

Care: Healthcare requires a multi-level approach more than ever. From primary to secondary care and from rural to urban areas we need to increase access to high quality care. We see improvements in care being supported by the opportunities that digital solutions offer. We envision that health care professionals have greater specialised knowledge on the diseases they treat, and that this knowledge is shared with patients. This knowledge should be reflected in improved follow-up and clinical guidelines, while digital approaches allow data to be generated that closes the loop of disease management. We envision care as a wheel where better follow-up leads to improved clinical guidelines, to better integration of real-world evidence in clinical trials, and finally to better health and patient reported outcomes.



2. INTRODUCTION

WHY FORM A VISION?

This Breathe Vision for 2030 is written against the context of a deficit of European level policy attention for respiratory health, and the need for unified voice. The aim is to increase impact by creating consensus on a clear set of overarching aims that respiratory partners can work towards. This Breathe Vision for 2030 is intended as a reference point for future advocacy actions, underpinning effective collaborative working that gains real policy making influence while also supporting the general awareness and understanding of respiratory disease in society. It has been formed from responses to an online survey and a workshop held during the spring of 2020 which sought to identify ways to take forward impactful advocacy for lung health in Europe.

This Breathe Vision paper has built on the activities, mission and vision of the current participants to draw out common ambitions in European level policy changes that have a real impact on patients' lives. Through an open discussion the interests, priorities and ideas for a vision for respiratory health in Europe have developed on what participants expect and hope to see by 2030. These activities also support discussions around the main priorities and goals providing the common reasons for the participant organisations to work together.

This is the first time that lung patient organisations and healthcare professionals have come together to focus on a vision for lung health. It is an important opportunity to build on significant successes, such as the research grants awarded by the IMI and the Horizon 2020 programmes and the EU air quality directive. However, there is still much progress to make. For instance, there have been no new classes of respiratory disease in 50 years. We continue to use and be guided by broad terms like asthma and COPD which still have no essential curative treatments, something that is also missing among rare lung diseases. On top of this we face new challenges in lung health due to the effects of climate change on air pollution.

One in eight of all deaths in the EU are due to respiratory diseases. Lung conditions cause at least 6 million hospital admissions per year¹

A HISTORY OF RESPIRATORY ENGAGEMENT AND DISENGAGEMENT

There has been a long period of joint or supported actions by the European level respiratory patient and professional community, such as the [Written Declaration on chronic respiratory diseases²](#) campaign supported by EFA, CF Europe, ELF, ERS and PHA Europe. There is also a history of co-ordinated advocacy efforts with five participants being involved in the ERN-Lung network

and three in EURORDIS. A smaller number of partners are also members of other organisations such as the WHO Global Alliance Against Respiratory Diseases (GARD) and the EU Civil Society Forum the European Public Health Alliance (EPHA) or Health and Environment Alliance (HEAL).

However, this work has missed a multi-partner collaboration and common call specific to advocacy for respiratory health to inform and advocate for EU and WHO Europe policy.

BRINGING PATIENTS AND PROFESSIONALS CLOSER TOGETHER

Respiratory professionals are at the forefront in providing policy evidence, but this can evolve further with the increased priority for respiratory research. An MEP Lung Health Group to connect to patients and improved patient representation on the pharmaceutical regulatory bodies should bring real policy impact. Equally, a wider collaboration would create structures for European advocacy within which information can be shared. Within this, participants would continuously identify opportunities aligned with common priorities. Advocacy centred learning opportunities can help build each organisations respiratory advocacy work, creating a reciprocal process of enhanced advocacy capacity achieving greater efficiency and impact on decisions supporting respiratory health and research.

ADDRESSING THE RESPIRATORY CHALLENGES IN THE CURRENT CONTEXT

The novel SARS-CoV-2 coronavirus and associated respiratory disease COVID-19 continues to dominate current thinking. This affords significant opportunities for respiratory health, but also provides some risks in terms of attention and focus away from the wider long-term respiratory issues that persist, despite the prevalence and impact for patients and society. This point in time is a unique opportunity for change, but calls for steering and influence to ensure that the needs, experience and views of respiratory patients and professionals are accounted for. Equally, the long-term impact on lung health in Europe and the additional burden on respiratory disease care services should be urgently addressed.





3. BREATHE VISION FOR 2030

The themes of this Breathe Vision bring together ambitions for 2030 in the areas of awareness, prevention, care and research. This vision also touches on the opportunities and threats that COVID-19 has introduced to respiratory health to place perspective on these developments.

3.1. RAISING AWARENESS OF RESPIRATORY DISEASE

With **600,000 people in Europe dying from respiratory disease each year and over 10 million life years lost (DALYs)²**, we need to expand knowledge around lung health and illness to drive change. We need more attention for the issues in respiratory health across all stakeholders, particularly the media, to gain a wider appreciation of the range of environmental, behavioural, genetic and other factors leading to respiratory disease and the impact that poor respiratory health has on physical wellbeing during people's lives³.

A UNITED AND EMPOWERED COMMUNITY

A common respiratory voice is formed: A united respiratory community should stand behind common goals, enjoying a strong voice which holds stakeholder attention. This voice would be leveraged through respiratory champions including patients and health care professionals. This would include re-inforcing the voice of GARD and aligning with their policy actions. Adopting common overall messaging will enhance the impact of advocacy efforts. **One respiratory voice will enhance effectiveness in advocating for policy change**, directly engaging MEPs through a European Parliamentary Interest Group or the MEP Lung Health group. Influencers should support this voice, speaking on behalf of respiratory diseases.

Patients are empowered: Respiratory patients are integrated into policy development and research across Europe to create impact and force change. **Patients are trusted voices for evidence and campaigners for change.** Embracing patients and their representatives should be second nature, and more commitment is needed to involve patients in all decisions that affect them.

People enjoy the right to know: People's right to know about the diseases that may affect them should be enshrined in policy, particularly as the importance of lung health is not well understood by the European public. Given this, new ways of reaching people should spread knowledge and awareness about how to find quality information. **A rights-based approach should provide someone with respiratory disease symptoms, but who is not yet a patient, a perspective on what disease they have.** Equally new ways should be developed to approach people who are not yet aware of their disease. Key lung disease issues should be common knowledge among the general public and politicians.

No more lung disease stigma: Lung disease should no longer be associated with self-inflicted harm, with a broad understanding that environmental exposure and occupational factors contribute to disease, as seen with COVID-19. **The stigma around tobacco smoking will be replaced with an understanding of harm prevention, early smoking cessation and stricter policies to reduce its commercialisation.** The perceived risk of transmission related to HIV, poverty, migration, or social marginalisation which is seen with tuberculosis and other infectious diseases should be thoroughly addressed and understood.

INFORMED DECISIONS

Undivided attention for lung disease: Under-diagnosis and misdiagnosis in respiratory disease must be reduced. Rare and less common respiratory diseases are often not diagnosed or are mis-diagnosed. Chronic obstructive pulmonary disease (COPD) often has a long diagnostic delay, while people diagnosed with asthma are eventually diagnosed with another disease. **Raising awareness will help patients get a diagnosis quicker and empower professionals** to identify these rare conditions, to trigger diagnosis through testing for co-morbidities. Patients with rare lung disease can help to do this as part of a more effective respiratory health intervention strategy, forcing more attention from policy makers.

All lung health stakeholders are engaged: With the high prevalence of respiratory disease a higher profile of lung health among health care professionals, industry and policy makers should be expected. **Increased global awareness on the prevalence, impact and severity of respiratory diseases should help to give lung health the place it deserves.** All stakeholders should use a common language, for example adhering to definitions of asthma and severe asthma. The collaboration on respiratory health advocacy will engage with this vision and reach out to other stakeholders.

Evidence-based information is ensured, countering misinformation: The COVID-19 pandemic has shown that misinformation can spread very fast from non-professional sources and become very difficult to redress. Tackling this phenomenon requires a **focused response, impetus and professional advice from the lung health community to ensure the best evidence is easily available.**

ADDRESSED POLICY GAPS

The EU Health programme explicitly addresses respiratory diseases. The recognition of respiratory health as a public health priority should provide a legislative hook for all the policies affecting respiratory disease. Relevant European Reference Networks (e.g. ERN-lung) can then be better leveraged for **specific actions, clinical research, environmental framework and climate change policies will link to better respiratory health outcomes,** resulting in systematic implementation of awareness and prevention campaigns. EU paediatric regulation should also be reviewed to account for respiratory health issues. A particular focus on lung health during childhood should be prominent, as this is a major predictor of ill health in adults, making it a valuable area for policy intervention.



Patient representatives participate in all decisions affecting them: By 2030 lung patients should be at heart of high-impact decision-making. From ethical and advisory boards ranging from research frameworks to EU strategies, to patient science presentations, lung patients should drive a needs-based agenda to promote change. **A strengthened, unified respiratory community should reach high political levels, addressing policy gaps and disease specific issues to gain the attention lung health deserves.** MEPs should enjoy strong and direct patient and professional input on decisions affecting patients. National level policy making should be equally impacted with patients involved in policy decisions.

Asthma prevalence in some European countries is amongst the highest in the world, with the Netherlands, Sweden and the United Kingdom having prevalence rates of 15% or higher^{4, 5}

Regulations are harmonised across Europe: Different rules lead to loopholes and to inequity in respiratory health across Europe. By 2030 the EU should **lead the way in advocating for the harmonisation of regulations that have a major impact on lung health.** This includes tobacco taxation and providing universal rights for treatment.

3.2. GREATER PREVENTION OF LUNG DISEASE

Only 3% of the health budget in Europe is spent on prevention⁶. This clearly limited expenditure seems to ignore the **very large cost-benefit ratio that prevention measures and harm reduction can have on the burden or cost of respiratory disease.** This percentage only includes direct investment, such as vaccination, but respiratory prevention needs to be embedded in all policies impacting health. Improving lung health literacy across all age groups is essential. This includes understanding how important lung health is for children and allowing and empowering people to better manage exposure to dirty air, tobacco and to make informed lifestyle choices.

NORMALISED PREVENTION APPROACHES

An EU Air quality framework is adopted: By 2030 everyone in Europe should be able to enjoy clean air. **A framework to address the issues of indoor and outdoor pollution and pollen should be implemented, filtering through to national policy.** This would follow adoption of the WHO air quality guidelines, committed to by over 50 patient and professional organisations. Air pollution costs over €1,000 per person per year⁷. Air standards would be no longer fragmented and neglected at the national level. They should be coherently addressed in one holistic framework which clearly lays out expectations, accountability and empowers lung patients and professionals for action through information. Air quality enforcement should be effective, including tackling individual choices such as wood burning. A tangible reduction in exposure to respiratory environmental risks must be seen.

8.6 months is the average loss of life expectancy in Europe due to poor air quality

Tobacco regulation becomes more stringent: A further reduction in tobacco usage should lead to an overall health improvement for all respiratory diseases and help reduce lung cancer and COPD incidence. **The Framework Convention on Tobacco Control should be**



implemented in all EU Member States, including better regulation to protect against second-hand smoke exposure. Other smoking products should be reviewed for regulation, with the EU setting aligned policies on the commercialisation, taxation and norms regulating tobacco and newer smoking products. Ultimately the sale of tobacco and its use should be banned in Europe.

In Europe, tobacco consumption is the most prevalent cause of death, responsible for around 16 % of all deaths in adults over 30 years old⁸

Risk factors are mitigated with sound policy making: Our approach to healthcare should pivot towards preventing disease. **Increased screening, particularly for rare respiratory diseases and lung cancer, and educating people on how to live with and manage their disease should become a normal part of the healthcare cycle.** Exposure to environmental pollution should be front of mind, influencing consumer, work and policy decisions. Policy revisions should consider prevention measures in all specific disease scenarios to deliver best responses. In addition, Eurobarometer data should be used to inform prevention approaches.

Abnormal lung growth is associated with 15-20% of deaths of newborn babies⁹

Secondary prevention measures become routine: Measures such as **screening, lung health checks, self-management and pulmonary rehabilitation**, which will be key for COVID-19 survivors with longer term lung damage, should be available to all to reduce and prevent deterioration, exacerbations or further illness for people living with respiratory disease. This will enhance quality of life and lead to longer lives. A programme of early screening should be established across Europe, recognising that respiratory diseases also lead to other chronic diseases.

Lung cancer becomes a less deadly chronic disease: Lung cancer is the biggest cancer killer in Europe, with over 20% of cancer deaths. **A very large benefit can be gained from better treatment and early interventions, such as screening rolled out across Europe.** With more effective **treatment** and smoking cessation, lung cancer would become a chronic disease.

The COPD curve is flattened: With greater awareness and earlier diagnosis the deterioration typically seen in COPD can be reduced **before rapid deterioration begins**, dramatically improving the lives of patients living with COPD.

Each year, more than 40,000 people die of tuberculosis in Europe¹⁰

Vaccines to address infectious lung diseases are improved and championed: Significant improvements in vaccines and their availability will tackle the situation we have today with 1 million people being hospitalised with pneumonia per year¹⁰, while **new vaccines are developed which address existing risk factors in tuberculosis.** Vaccine hesitancy should also be reduced by championing vaccination to protect vulnerable people, building on the public attention received during the COVID-19 pandemic. Respiratory patients need to have the information on vaccinations to be able to adhere to vaccination plans. The WHO European Immunisation Agenda 2030 aims to leave no-one behind and should be fully supported by all health agencies in Europe.



3.3. GETTING THE RIGHT CARE

The right to quality care should be the basis for respiratory care related policy, addressing health inequalities across Europe and enabling productive and rewarding working and school lives. Although within 10 years no cures are expected and many promising developments may not resolve into solutions, it is also a long enough time to expect step changes in the way that we approach lung health.

CARE IS A RIGHT THAT IS ACTED UPON

Timely and accurate diagnosis for lung diseases is guaranteed: By 2030 diagnosis of lung disease should no longer occur late for those in need. Validated self-checks can step up the process of diagnosis. Testing and wider application of screening, such as low-dose CT screening for lung cancer, will **open understanding of the range of diseases and co-morbidities, leading to silo's being removed from healthcare.**

16 % of asthma and COPD patients initially received a wrong diagnosis, taking on average between 4.5 and 5.2 years to receive a correct diagnosis¹¹

Lung patients get the right treatment at the right time: A transition to more exact approaches with personalised treatment and therapy should be in place by 2030, leaving behind the idea of one-treatment-fits-all. **The right treatment for the right patient should be delivered by analysing individual patient data to create tailored treatment plans across Europe, with everyone getting the re-imburement they need to access that treatment.** Multi-disciplinary care should be available whenever it is needed for lung disease patients. The gap between European counties in the provision of care should be addressed and the principle of equity should drive policy decisions. Quality of life should lie at the heart of all treatment outcomes, with a co-morbidities approach adopted for treatment and care that accounts for non-pharmacological approaches and is verified against guidelines.

Equal access to care monitored by Key Performance Indicators: Inequal access to testing, treatment and care severely affects individual's lung health. **An improvement in inequities should be forged,** monitored by developing agreed European level Key Performance Indicators which are analysed for regulars during the coming 10 years.

Every patient has a self-management plan: E-medicine should have addressed the fact that two-thirds of patients (asthma and COPD) report not having a self-management plan and one third declare that they have not heard about self-management plans¹². **Patient pathways and self-management plans should also be formalised across Europe and promoted by health care professionals.** Health literacy should be advanced to support this approach.

More than 90% of influenza-related deaths occur in patients in the older age group¹³



Digitalising respiratory health, care and patient communities: Digital health will drive change in providing access to quality health, with patients at the heart of the technological developments. The WHO Europe initiative on empowerment through digitalisation should be acted upon. **Lung patients should be able to access virtual monitoring of disease progression providing flexible, responsive, and timely care.** Care should have moved forward through technology providing patients the information they need on a daily basis. Remote consultations should also reduce costs, with the digital divide in lung disease addressed. The opportunities and risks must be well managed during the deeper integration of technologies in research, care and daily lives while supporting the patient-doctor core relationship.

Active lives are enabled: The economic potential of better treatment for respiratory disease is huge. The impact of disease on people's lives should be proven by better respiratory health economics data showing the economic value of good working and schooling lives. This should help drive investment in prevention measures, with meaningful Return on Investment (ROI) figures enabling policy change. **The legal protection of lung patients should also be addressed, where disability is often the only legal avenue to protect rights.** Factors that affect working and school lives should be tracked in order to influence policy changes. The more direct the relationship between policy and economic impact the more likely it is to have impact.

Medication is improved for children with lung disease: Our understanding of how to medicate children should be advanced, protecting the next generation. Lung health in children is vital and a key predictor of ill health in adults. Furthermore, 12% of infant deaths in Europe are due to respiratory illness, according to WHO Europe. **More research effort should deliver new medication and tailored treatment approaches, with secondary treatments, like rehabilitation, made commonplace.** Legislation on medicines for children should be revised to improve the treatments available.

Well managed adolescent and young adult care: **The transition from childhood asthma care to adult care can be difficult to manage. Patients can fall between the gap, a point exacerbated when this group often under report their disease symptoms. A clear framework should be in place which states how the transition should happen,** supported by a centre of excellence covering the transition from child to adult services.

Address care for long term effects of infectious disease: As with COVID-19, the long-term impact of **reduced lung-function resulting from infectious diseases such as tuberculosis, pneumonia and influenza, should be addressed as a priority.** This is urgent given that the anticipated volume of people with lung health issues as a result of COVID-19 will add to the already large scale impact on long term care of other infectious diseases.

The total annual cost of respiratory disease in the EU is 380 billion Euros¹⁴



3.4. ADVANCING RESEARCH INTO LUNG HEALTH

While Europe is at the forefront of health research, more effort and support is needed in researching lung health to sustain the increase in understanding and to find the major new treatments that have been missing for the past 50 years in COPD and Asthma. Leveraging digital health and technological opportunities, sharing data and analysis more widely and creating frameworks that deliver faster results can help make real advances in lung health treatment.

BETTER RESOURCED INNOVATIVE AND EFFICIENT RESEARCH

Patient priorities are put at the centre of research: Patient priorities should set the agenda for research. Broad-based patient input on funding decisions becoming the standard across Europe in order to reflect the changes lung patients want to see in their lives. Patients should also participate in steering committees for research projects for the life course of each project.

Clinical trials are made more efficient: The wide range and scale of respiratory disease demands more innovation and these innovations to be spread widely. This includes **better clinical trial design, real world trials to support the development of interventions, digital clinical trials handling large amounts of data and novel platform trials which better identify which treatments work for which patients.** In addition new approaches are needed to get more lung patients participating in clinical trials. To help push research further and faster a stronger focus on academic input and independent clinical trials is also needed together with an overhaul of pharmacological-patient regulation.

Advancing treatments towards a cure: Respiratory health has traditionally been underfunded in relation to other diseases. This important given its impact on the health of Europeans. A simple matter of more resource is important for protecting and dealing with the health and socio-economic impacts of respiratory disease. Situations like the lack of breakthroughs in treating COPD and asthma over the last 50 years need to be addressed – respiratory disease remains the 3rd cause of death worldwide¹⁵. **More research, incentivised to find effective treatments, will bring us closer to cures and we should have clear orphan drug type incentives.** Better treatment regimens are also needed for infectious diseases, such as tuberculosis where long, complex, and outdated treatments with severe side effects are still being used.

Coherent frameworks are in place for discovery and care improvement: Money alone will not solve all the problems. Working together should be supported, ensuring that the power of the collective is harnessed in a structured and meaningful way. Research partnerships should see fundamental changes in the depth and level to which working together is achieved, with a focus on strategies to reduce the cost of drug development. **Data and data gathering should be better managed and shared more widely, leveraging enabling technology to analyse multiple datasets to better understand the complexity of respiratory disease.** Patients need to be happy that their data is being properly used to facilitate better care and research. Rare disease legislation revision should be revisited, and improvements proposed. These frameworks should also focus on patients adhering to treatment and practicing prevention measures.



Environmental health science and epidemiology is leveraged: A research focus dedicated to environmental health and focused on risk and prevalence should identify the scope of the challenges. **This focus should be in both infectious diseases, such as tuberculosis, and non-infectious diseases, such as asthma and COPD.** This approach should ensure a balanced health policy response, minimising crisis management. Research on the short and long-term impacts of new smoking products should be supported to better understand their impact, as well as indoor environmental pollution and risks to respiratory health in the workplace.

For many lung diseases, recorded hospital admissions and deaths are only the “tip of the iceberg”

Digital technology is harnessed to drive change: Technology should be used to encourage and exploit respiratory partnerships and deliver step changes for the patient experience. **Tools like artificial intelligence and computer modelling can make both research and clinical trials more efficient provided they are adopted.** New technologies should be embraced, and their adoption should not be hindered. Digital technologies should also be leveraged to enable better diagnosis and self-management, including recognising machine learning as a way to improve early diagnosis and patient sensitive use of artificial intelligence.

Innovation is fostered through registries and biobanks: Our understanding of respiratory disease should be deepened by **using registries and biobanks to share non-sensitive information more widely and effectively**, and by creating a joint coding approach across Europe to enable data sharing. A movement towards respiratory registries and biobanks should also enable us to have more European lung patient cohorts and clinical trial networks.

New drugs get to patients’ faster: The innovation and regulatory pipeline should work more efficiently, **including getting more lung patients to participate in and design clinical trials, accelerating progress with new ideas.** The seven years of EU research funding from 2021 will have seen billions of euros delivering more impact on the lung health discovery pipeline. Drug repurposing should receive more attention, using existing solutions where they are effective. New drugs would be quality drugs with fewer side effects.

Accurate European wide respiratory health data is developed: Much of the data we rely on is old – sometimes as much as 10 years old - while other data is not collected or not released at a national level. **Reliable data on prevalence and the burden of respiratory disease is vital to better quantify the problem and to focus our response.** This should be complimented by patient stories and experiences which show what this data means.

Whole care genetics and whole-body approach: Diseases continue to be seen in silo’s, despite a number of good initiatives. This approach is reflected in the genetic field as well as in clinical trials. **A whole-body approach should be taken as a starting point for all research** to better understand the interlinked functioning of organs and co-morbidities and to ensure faster progress in finding cures. The transition from child to adult care would form part of this approach, as would the link between infections and chronic disease.



3.5. ADDRESSING COVID-19 THREATS AND SEIZING THE OPPORTUNITIES

The novel SARS-CoV-2 coronavirus and associated respiratory disease COVID-19 has highlighted the importance of respiratory health. This affords a once in a lifetime opportunity to concentrate minds on resources and to build unmet needs into the new EU health programme.

A LONG-TERM RESPONSE IS BALANCED AGAINST ALL RESPIRATORY NEEDS

Sustainable health systems improve preparedness for health emergencies: COVID-19 has highlighted the need to be better prepared for respiratory viruses or viruses that enter via the respiratory system. The appetite to invest in better preparedness should be exploited through funding programmes and be reflected in policy changes. Better international coordination on respiratory viruses and infections should emerge, including a European biomedical research agency. **The leap in the use and development of remote monitoring services and digitally enabled trials which work better for people with respiratory disease should be maintained and extended.** Preparedness measures should take account of wider lung health issues with a holistic approach to respiratory health at their heart. This would include planning for the needs of existing respiratory patients.

COVID-19 survivor needs are met: COVID-19 survivors represent a new respiratory health challenge. As the COVID-19 advances, we are seeing that many survivors are left with a range of respiratory and other health issues. **Specific needs for people left with lung damage will increase in the burden on patients and demands on respiratory health services.** A blend of in person and digital care should help address patient need. As this situation evolves, we expect a measured and evidence-based policy response. Damaged lungs affect all aspects of life and many people will require long-term support. Issues of diversity and impact on population groups should be focused on in managing survivor needs.

The Non-Infectious Diseases epidemic is tackled: One risk with the focus on COVID-19 is that policy may pivot towards infectious diseases, such as tuberculosis, at the expense of non-infectious, chronic lung diseases such as asthma, pulmonary hypertension and COPD. Given the impact on and vulnerability of people with respiratory disease to COVID-19 we envisage **a balanced response to COVID-19 that enhances attention to chronic non-infectious diseases and existing infectious diseases.** This should take care not to overshadow the widespread and serious nature of these existing lung diseases. In addition, the impact of COVID-19 on the range of respiratory patients should be addressed, including the provision of targeted and specific information and measuring the impact COVID-19 has on the outcomes of lung diseases.

Prior to COVID-19, non-infectious diseases accounted for 86% of deaths and 77% of the disease burden in the WHO European Region¹⁶





4. BUILDING A VISION FOR THE FUTURE OF RESPIRATORY HEALTH

WHO IS THE VISION AIMED AT?

The Council of Europe definition of Europe¹⁷, including 47 member states, is used wherever we talk about Europe in this paper. However due to practical concerns and the leadership role the EU plays in Europe, the EU and its institutions are the main target of this BREATHE Vision for 2030. WHO Europe is the second target, due to its role in non-EU countries where links to national level decision making is important. The WHO Non-Communicable Disease Global Monitoring Framework revision ending in 2025 should include ambitious targets for lung diseases, focusing on reducing preventable deaths linked with respiratory health.

CHANGES IN THE LANDSCAPE

While the associated economic issues we are seeing with the pandemic may affect development efforts, it could also be a driver to explore more cost-effective ways of working and to evaluate where the biggest impact can be achieved.

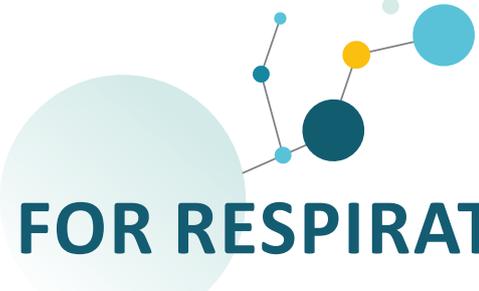
The vision that this paper works towards has specific meaning for our key stakeholders.

Policy makers in Europe: For national and European policy makers, this Vision should be used as a guide for the priorities of respiratory patients and professionals. It should result in a more coherent and louder voice for the respiratory community at the European level. Patients expect more attention from policy makers and for their experience to be recognised in fully thought-out healthcare approaches that address the insufficient attention that respiratory health currently receives.

Respiratory organisations and associations and public health organisations: This Vision paper can help form common messages and a common voice for those working in lung health and can be used as a hook for organisations own messages. It can also help to highlight the lack of attention that the respiratory sector receives at national and regional levels. GARD comes to mind in particular as it is committed to the vision of “a world where all people breathe freely” and has adopted key priority areas that relate to the UN Sustainable Development Goal 3.4¹⁵ and which align with this Breathe Vision for 2030, including: improving the care of chronic respiratory diseases and addressing health inequalities; advocating for action with a strong, unified voice; and supporting patient-centered research.

Pharmaceutical and industry partners: Industry partners can draw on this vision to understand where the priorities for respiratory patients and professionals lay and understand that the expectation is to increase efforts focusing on innovation. The vision looks to a partnership with industry and to work together on key enabling factors which can advance development in treatment and healthcare.





5. A VISION FOR RESPIRATORY HEALTH IN 2030

By 2030 diagnosis, cure and disease management should be central to respiratory health policy decisions. Significant progress is achieved in digital technologies for empowering patients. Specific actions should be in place to address risk factors common to all respiratory diseases, reducing the threat to health.

SAVE LUNGS FOR LIFE, A EUROPE WHERE EVERYONE CAN BREATHE

Our vision for 2030 is a Europe with:

VOICE A common voice for the respiratory community, which is listened to at the highest political level

- Protection of respiratory health is embedded into EU policymaking with specific key policy targets and actions set in the WHO Non Communicable Disease Global framework for Europe

ACCESS Measurable progress in equal access to the best care and treatment across Europe

- Full reimbursement of medications, home treatment and expert care is in place
- There is a fully developed personalised medicine approach delivering the right treatment for the right patient
- Lung patients are empowered for self-management and information through digital solutions, acting upon the WHO Europe Empowerment through Digital Health initiative

DIAGNOSIS Measurable progress in correct and early diagnosis in all respiratory diseases for quality, productive lives

- Time matters and all diseases need to see faster diagnosis to enable effective treatment
- A right to know what disease an individual has empowers people with symptoms to gain full diagnosis, including routine diagnosis through co-morbidities
- Cost and capacity savings from better management of disease as a consequence of early diagnosis will help health services respond to the growing challenge of respiratory disease
- Rare respiratory diseases are recognised, or symptoms lead to referral, by all physicians

BREATHE FREELY Clean air for everyone

- Air quality affects everyone. A fundamental right to clean air should be enshrined in EU policy
- Smoke free environments should become the norm, and a decline of major air pollutants in line with WHO Air Quality guidelines

RESEARCH to prevent, cure and care Investment on respiratory healthcare and research is doubled

- Smarter approaches speed up innovation, driving innovative clinical trials leading to faster access to treatment
- Coherent frameworks are in place for discovery and care improvement
- Novel vaccinations are focused on providing a more effective response for long existing infectious diseases such as tuberculosis
- The prevalence of respiratory diseases is fully understood with a research focus enshrined in policy, helping us to identify the scope of the challenges
- Lung cancer becomes a chronic disease due to safe diagnosis and treatment
- Technological advances have enabled better symptom management, diagnosis and research
- Evidence is gathered, shared and utilised faster by better and more open use of digital solutions

MEASURABLE PROGRESS towards embedding lung patients into policy development and research across Europe

- Including the patient perspective in all areas, from policy development to integration in research projects to decisions about own care and treatment
- Patients are empowered to participate in all decisions that affect them. Nothing should be decided about patients without patients.

A PREVENTION APPROACH to respiratory disease guides policy making decisions that impact on patient and population health

- Disease and disease severity are strongly impacted by preventable factors, such as indoor air pollution, tobacco harm, chemical exposure and screening for lung cancer, cystic fibrosis, tuberculosis and other diseases
- Unity in tackling tobacco epidemic and moving towards no tobacco
 - No child between 12-18 should be in touch with cigarettes
 - Taxation of tobacco should increase
 - Policy and taxation alignment across European countries to avoid cross-border competition on tobacco products
- Health economics data specific to respiratory health have built a true understanding of the value of lung health
- A better public understanding of respiratory disease and disassociation with behaviour is achieved among the population of Europe
- Secondary prevention measures are available to all patients reducing and preventing deterioration or further illness for people living with disease





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European Idiopathic Pulmonary Fibrosis and Related Disorders Federation (EU-IPFF)

European Lung Foundation (ELF)

European Respiratory Society (ERS)

Lung Cancer Europe (LuCE)

Pulmonary Hypertension Association Europe (PHA-E)

Tuberculosis European Coalition (TBEC)

For more information on the Breathe Vision for 2030 please visit www.breathevision.eu/about

GLOSSARY

EPHA: European Public Health Alliance
ERN-Lung: European Reference Network - Lung
ERS: European Respiratory Society
EU: European Union
EURORDIS: The European Organisation for Rare Diseases
IMI: Innovative Medicines Initiative
GARD: WHO Global Alliance Against Respiratory Diseases
HEAL: Health and Environment Alliance
Horizon 2020: EU funding programme for research and innovation
MEP: Member of the European Parliament
SARS-CoV-2: Severe Acute Respiratory Syndrome coronavirus 2
SDGs: the United Nations Sustainable Development Goals
WHO Europe: World Health Organisation Europe

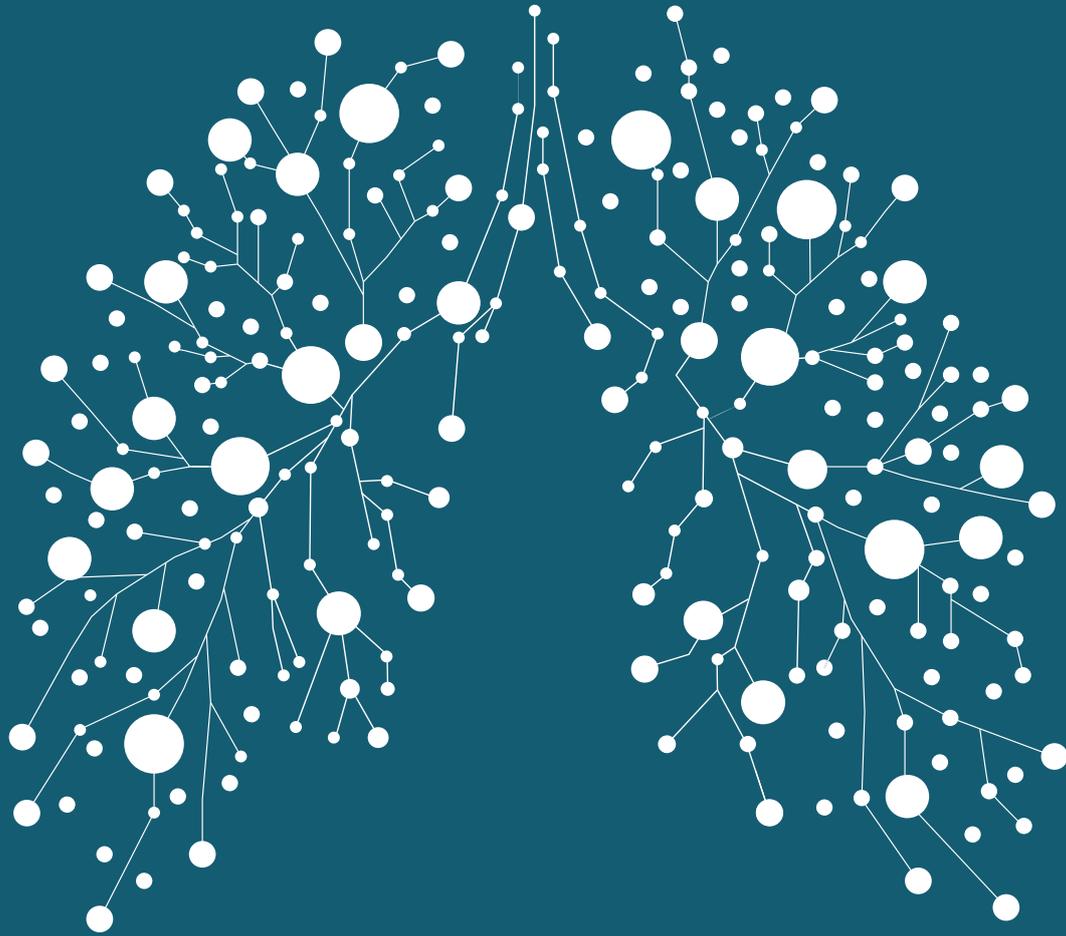


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