

EUROPEAN COMMISSION

DIRECTORATE-GENERAL FOR HEALTH AND FOOD SAFETY

Public health

Health promotion, disease prevention, financial instruments

Healthier Together – EU NCD Initiative

The EU NCD Initiative addresses five strands: a) cardiovascular diseases, b) diabetes, c) chronic respiratory diseases, d) mental health and neurological disorders, e) health determinants.

Contribution from health stakeholders is essential to gather:

- 1. **priorities for action** in each of the above-mentioned strands;
- 2. **examples of effective policies, best practices, promising approaches**, innovative actions (to be put for consideration of Member States) to effectively address priorities;
- 3. the **field of work of stakeholders** and actions that stakeholders can do in collaboration with public health authorities and other parties.

Stakeholders may also wish to provide general comments (on the structure of the approach, information gaps, recommendations for better supporting stakeholders, etc.).

How to contribute

You can provide input –or <u>revise and add to your previous input</u> – at any time until the end of the drafting process of the EU NCD Initiative, expected by June 2022. However, contributions will be particularly appreciated before the webinars, to feed the debate.

When you are ready to do so,

- 1. Download the document from the Health Policy Platform;
- 2. Introduce your input; please be concise;
- 3. Save and send the document to contact@euhealthsupport.eu;
- 4. Revise and resend the document in case you wish to update your input. The previous version will then be replaced.

We may contact member of the Health Policy Platform NCD Stakeholder Group for clarifications. Unless you disagree, responses will be uploaded to the Health Policy Platform and thus readable by other network members. For that reason, please do not include personal information (e.g. names and contact details) in your document.

Calendar

Member States' webinars Stakeholders' webinars • 3 February 28 January 17 March 3 March 8 April 27 April 3 June 19 May You will receive a notification when new materials are available at the Health Policy Platform, including summaries and drafts of the EU NCD Initiative and/or new questions for stakeholders. https://ec.europa.eu/health/non communicable diseases/overview en **Stakeholder input** 1. Please provide the name of the organisation you represent.* Individual names will not be disclosed; the list of responding organisations may be published. European Federation of Allergy and Airways Diseases Patients' Associations (EFA) Input will be considered from organisations listed in the EU Transparency Registry and granted access to the EU NCD Initiative Stakeholder Network at the Health Policy Platform. 2. On which strands of the EU NCD Initiative would you like to comment? Please select all that apply. ☐ Cardiovascular diseases Diabetes Chronic respiratory diseases Mental health and neurological disorders

You can then fill in the relevant sections below. If you only fill in one section, please add any general comments you may have in the closing section.

Health determinants

1. Please indicate your **priorities for EU-supported action** in this strand.

Please select up to five priorities and be as specific as possible. You may provide a short clarification on why these priorities rank high and add relevant links (e.g. scientific literature, reports of reference institutions, policy documents).

	References
Climate change) Prepare and respond to climate change events affecting human health and mortality such as heatwaves, floods, wildfires, changes in pathogens Climate change is a planetary emergency and a cross-border phenomenon. While the EU is adopting policies to adapt and mitigate climate change, it is lagging behind in the preparedness and response on climate change effects on health. Currently, there is no EU legislative framework for coordinated actions on heatwaves, floods, wildfires and pathogens and these impacts have not been taken up by the newly established Health Emergency, Preparedness and Response Authority (HERA). There are several manifestations of climate change that present serious concerns for respiratory health. For example, extreme temperatures during heatwaves increase morbidity and mortality of respiratory conditions; wildfire smoke contains many dangerous pollutants that threaten public and respiratory patient health; while increased floods from rising sea levels and extreme precipitation events result in higher concentrations of mold as well as mold spores in the atmosphere.	 C. Åström et al., 'Heat-related respiratory hospital admissions in Europe in a changing climate: a health impact assessment', 2012, https://bmjopen.bmj.com/content/3/1/e001842 D. D'Ippoliti et al. 'The impact of heat waves on mortality in 9 European cities: results from the EuroHEAT project', 2010 https://pubmed.ncbi.nlm.nih.gov/20637065/ C. E. Reid et al. 'Critical Review of Health Impacts of Wildfire Smoke Exposure', 2016 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5010409/ M. De Sario et al. 'Climate change, extreme weather events, air pollution and respiratory health in Europe', 2013 https://erj.ersjournals.com/content/42/3/826 L. A. Ziska et al. 'Temperature-related changes in airborne allergenic pollen abundance and seasonality across the northern hemisphere: a retrospective data analysis', 2019 https://www.thelancet.com/journals/lanplh/article/PIIS2542-5196(19)30015-4/fulltext A. Damialis, C. Traidl-Hoffmann et al. 'Climate Change and Pollen Allergies', 2019 https://link.springer.com/chapter/10.1007/978-3-030-02318-83 J. A. Poole et al. 'Impact of weather and climate change with indoor and outdoor air quality in asthma: A Work Group Report of the AAAAI Environmental Exposure and Respiratory Health Committee', 2019 https://www.jacionline.org/article/S0091-6749(19)30281-7/fulltext S. Z. Deng et al. 'Climate change, air pollution, and allergic respiratory diseases: a call to action for health professionals', 2020

2	(Air quality) Achieve high standards of air quality indoors and outdoors	Air pollution represents the single largest environmental health risk in Europe. Despite being preventable via appropriate measures and policies, still today air pollution is a leading environmental cause of mortality and disease in Europe and globally. Only in the EU, it is associated with over 400,000 premature deaths per year. Tand citizens rank air pollution among the three most pressing environmental issues. Exposure to air pollutants such as PM2,5, NO2 is directly linked to the development and worsening of respiratory diseases such as asthma and chronic obstructive pulmonary disease (COPD). Meanwhile, it significantly increases their disease burden, including more hospitalisations and visits to the emergency department, economic and social costs and an unquantifiable human distress. Indoor air pollution from biological agents related to damp and mold increases the risk of respiratory disease in children and adults. Children are particularly susceptible to the health effects of damp, which include respiratory disorders such as irritation of the respiratory tract, allergies and exacerbation of asthma. Damp is often associated with poor housing and social conditions, poor indoor air quality and inadequate housing hygiene, which includes factors such as overcrowding, low air exchange rate, low indoor temperature and poor insulation. Children subject to higher exposure to poor air quality indoors are at greater risk of being affected by outdoor pollutants.		European Environment Agency, Air Quality in Europe, 2020 report, https://www.eea.europa.eu/publications/air-quality-in-europe-2020-report Special Eurobarometer report 501, 2019 'Attitudes of Europeans towards the Environment' https://europa.eu/eurobarometer/surveys/detail/2257 XY. Zheng et al. 'Short-term exposure to ozone, nitrogen dioxide, and sulphur dioxide and emergency department visits and hospital admissions due to asthma: A systematic review and meta-analysis', 2021, https://pubmed.ncbi.nlm.nih.gov/33601224/ A. J. Cohen et al. Estimates and 25-year trends of the global burden of disease attributable to ambient air pollution: an analysis of data from the Global Burden of Diseases Study 2015, 2017, https://www.thelancet.com/journals/lancet/article/PIIS0140 -6736(17)30505-6/fulltext A. I. Tiotiu et al. 'Impact of Air Pollution on Asthma Outcomes', 2020, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7503605/ I. Annesi-Maesano 'Air Pollution and Chronic Obstructive Pulmonary Disease Exacerbations: When Prevention Becomes Feasible', 2019 https://www.atsjournals.org/doi/10.1164/rccm.201810-1829ED M. Hulin et al. 'Respiratory health and indoor air pollutants based on quantitative exposure assessments', 2012 https://erj.ersjournals.com/content/40/4/1033
3	(Environmental exposure) Address the impact of environmental	At any given moment, even before birth, we are subject to environmental exposures that may boost our health, reinforcing our immune system response. However, other substances might harm our	-	The European Human Exposome Network (EHEN) https://www.humanexposome.eu/ . The world's largest

exposures on respiratory health over the whole life course and introduce the biodiversity hypothesis in everyday life health, exacerbating existing diseases or even triggering them from scratch.

Scientific research has recently opened new horizons on our knowledge on the impact of the environment on certain diseases such as allergy, asthma and COPD. Exposure to nature and rich diets might act as protective mechanisms, while exposure to chemicals, pollution, food, tobacco, infections and various types of allergens are environmental factors that can act as respiratory sensitisers/irritants, trigger inflammations in the airways and/or destabilize the immunological system.

The understanding of the variety of ways in which the environment is impacting human health can open new horizons in the assessment and prevention of environmental risks. Moreover, it emphasises on the value of a true One Health approach that reconciliates human health, animal health and the environment, and can offer huge benefits to all three of them.

- network of projects studying the impact of environmental exposure on human health, from conception to death.
- The European Human Biomonitoring project (HBM4EU)
 https://www.hbm4eu.eu/. The project develops evidence on the actual exposure of citizens to chemicals. It also provides for robust interpretation of human biomonitoring data and the possible impact of chemical exposure on human health, using the most up to date scientific tools
- C. M. Eckhardt, H. Wu 'Environmental Exposures and Lung Aging: Molecular Mechanisms and Implications for Improving Respiratory Health', 2021 https://pubmed.ncbi.nlm.nih.gov/34735706/
- H. T. Mocelin, G. Bueno Fischer, A. Bush 'Adverse early-life environmental exposures and their repercussions on adult respiratory health', 2022, https://www.sciencedirect.com/science/article/pii/S0021755
 721001650
- J. M. Collaco et al. 'Influences of environmental exposures on preterm lung disease', 2021, https://www.tandfonline.com/doi/abs/10.1080/17476348.2 021.1941886
- S. Dick et al. 'Associations between environmental exposures and asthma control and exacerbations in young children: a systematic review', 2014, https://bmjopen.bmj.com/content/bmjopen/4/2/e003827.fu
 II.pdf
- C. Sarkar et al. 'Environmental correlates of chronic obstructive pulmonary disease in 96 779 participants from the UK Biobank: a cross-sectional, observational study', 2019, https://www.thelancet.com/journals/lanplh/article/PIIS2542
 -5196(19)30214-1/fulltext

	generation by 2040
	Union tobacco-free
	Ensure a European
4	(Tobacco control)

Tobacco consumption is the leading preventable risk factor of mortality in Europe, with disproportionately high rates compared to other parts of the world, both in terms of smoking rates and proportion of deaths attributable to tobacco. Evidence shows that there is no safe level of exposure to tobacco smoke: active tobacco use still accounts for over 907.000 deaths. In addition to smoking being the number one risk factor of lung cancer, it is a key contributor also to other chronic respiratory diseases. Smoking is the leading cause of COPD, which is the third leading cause of death worldwide.

Novel tobacco and related products, such as electronic cigarettes and heated tobacco products, are being commercialized largely as alternatives to conventional tobacco and becoming popular among the youth. This is despite emerging evidence pointing towards the harmful effects of these products too on human health.

Exposure to second-hand smoke is responsible for over 73,000 deaths. There is solid evidence on the damaging effects of smoking and exposure to second-hand smoke on health, both in the short and long term. Smoking and exposure to tobacco smoke are major triggers for asthma and allergy symptoms. Finally, active or passive smoking has been shown to be a major health risk in particular during pregnancy, for both women and the unborn babies.

- WHO European Region report, Tobacco and inequities
 Guidance for addressing inequities in tobacco-related harm,
 2014,
 https://www.euro.who.int/__data/assets/ndf_file/0005/247
 - https://www.euro.who.int/ data/assets/pdf_file/0005/2476 40/tobacco-090514.pdf
- Global Burden of Disease Tool
 https://ghdx.healthdata.org/gbd-results-tool?params=gbd-api-2019-permalink/4404bd4bd4bd4b6fea3b85e4a7926ed4909d
- Special Eurobarometer report 506, Attitudes of Europeans towards tobacco and electronic cigarettes, 2021, https://europa.eu/eurobarometer/surveys/detail/2240
- A. Tzortzi et al. 'Passive exposure to e-cigarette emissions: Immediate respiratory effects', 2018 https://pubmed.ncbi.nlm.nih.gov/32411845/
- F. T. Filippidis, et al., 'Two-year trends and predictors of ecigarette use in 27 European Union member states', 2017 https://tobaccocontrol.bmj.com/content/26/1/98
- R. Laniado-Laborin 'Smoking and Chronic Obstructive Pulmonary Disease (COPD). Parallel Epidemics of the 21st Century', 2009,
 - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2672326/
- A. Tiotiu et al. 'The Impact of Tobacco Smoking on Adult Asthma Outcomes', 2021,
 - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7908240/
- G. Calogero et al. 'Influence of cigarette smoking on allergic rhinitis: a comparative study on smokers and non-smokers', 2019.
 - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6776172/
- S. J. Chung et al. 'Novel tobacco products including electronic cigarette and heated tobacco products increase risk of allergic rhinitis and asthma in adolescents: Analysis of Korean youth survey', 2019, https://pubmed.ncbi.nlm.nih.gov/32003899/

5	(Consumer products)
	Ensure safe information
	through proper labelling
	in the EU single market,
	even in emergency
	times

Daily consumer products, such as food, medicine, clothing, detergents or cosmetic products, often contain substances that are potentially harmful for people living with chronic conditions such as allergy, asthma and COPD. The EU must safeguard the right to accurate and timely information of consumers through appropriate labelling.

The presence of **allergens in food products** can be life-threatening for people living with food allergy. Via the Food Information to Consumers regulation 1169/2011, the EU has taken measures to ensure the labelling of allergenic ingredients in a way that protects consumers with food allergy and prevents the risk of anaphylaxis.

Food-related labelling provisions must serve as a model for informing consumers of **potential risks in consumer products** too e.g. fragrance allergens contained in perfumes and other cosmetic products, chemicals present in clothes and linked with skin allergies, food allergens used in medicines as excipients etc. It is absolutely important that the level of information, and therefore of health protection, is safeguarded at all times, even during emergencies.

Bodies such as the European Food Safety Authority (EFSA), the European Medicines Agency (EMA) and the European Chemicals Agency (ECHA), can play a key role by assessing the health risks and publishing relevant guidelines and recommendations.

- European Federation of Allergy and Airways Diseases
 Patients' Associations (EFA), 'FoodDetectives report Quality
 of Life for People with Food Allergies in Europe: A Menu for
 Improvement'
 - https://www.efanet.org/images/EFA FoodDetectives Report .pdf
- B. I. Nwaru et al. 'Prevalence of common food allergies in Europe: a systematic review and meta-analysis', 2014, https://pubmed.ncbi.nlm.nih.gov/24816523/
- A. Steinemann 'Fragranced consumer products: effects on asthmatics', 2018, https://pubmed.ncbi.nlm.nih.gov/29391919/
- C. Svedman et al. 'Textile Contact Dermatitis: How Fabrics Can Induce Dermatitis', 2019,
 - https://link.springer.com/article/10.1007/s40521-019-0197-5
- J. Kelso 'Potential food allergens in medications', 2014, https://www.jacionline.org/article/S0091-6749(14)00432-1/fulltext

2. Please provide your selection of **effective policies, best practices, promising approaches** and innovative actions (to be put for consideration of Member States) to effectively address the priorities.

	Effective policies, best	Rationale	References
	practices, promising		
	approaches or innovative		
	actions		
1	(Climate change) Establish	The EU has wide-ranging competences in the area of climate	- World Health Organisation (WHO) action on Building climate-
	real-time monitoring and	change and a flagship strategy, the EU pGreen Deal.	resilient health systems https://www.who.int/teams/environment-
	information thresholds for	Meanwhile, the EU should have a strong role adding value to	climate-change-and-health/climate-change-and-health/country-
	climate change related air	country-level efforts and initiatives tackling the effects on	support/building-climate-resilient-health-systems
	pollutants such as pollen	health.	- EU Autopollen project (2018-2022) aims to provide information and
	and sand/dust storms;	Pollen and sand/dust storms are risk factors affecting health	recommendations for the establishment of automatic pollen
	Strengthen and coordinate	that are directly linked with climate change. The warming of	networks and the development of related products based on real-
	the aerobiology monitoring	the planet increases the amount of pollen and other	time pollen data
	and surveillance network	aeroallergens in the atmosphere, boosts their allergenicity	https://www.eumetnet.eu/activities/miscellaneous/current-
	towards a modern and	and prolongs the pollen season. Meanwhile, sand and dust	activities-mi/autopollen/
	coordinated EU pollen count	storms are facilitated by dry conditions and rising	- EU Atopica project (2011-2015) . The EU research project improved
	network inspired by the	temperatures.	understanding on the impact of climate change, land use and air
	AutoPollen Initiative	<u>.</u>	pollution on human health, in particular ragweed pollen induced
		Since both pollen and sand/dust storms represent a serious	allergies. It found that air concentrations of allergenic ragweed
		threat to respiratory health, real-time information and	pollen could quadruple in Europe by 2050, with climate change
		forecast can prove vital for people with respiratory allergy	being responsible for two thirds of this increase.
		and asthma. Accordingly, specific information thresholds can	https://www.atopica.eu/Default126f.html?section=376
		trigger immediate information alerting the public and	- European Climate and Health Observatory, Workplan 2021-2022,
		vulnerable groups, facilitating preventative action.	https://climate-
			adapt.eea.europa.eu/observatory/About/european_climate_and_h
<u> </u>			ealth observatory workplan 2021 22.pdf
2	(Climate change) Include	They EU has the competency for climate action, that could	- World Health Organisation (WHO) action on Building climate-
	surveillance, preparedness	increase its operations across other competencies such as	resilient health systems https://www.who.int/teams/environment-
	and response to climate	public health through:	climate-change-and-health/climate-change-and-health/country-
	change-related hazards	- Expansion of the current plan of the European	support/building-climate-resilient-health-systems
	affecting health clearly	Observatory on Climate Change and Health, to	- European Climate and Health Observatory

		man-made or natural disasters, but also in case of extreme climate events such as heatwaves, in close cooperation with its national counterparts, the EU Health Preparedness and Response Authority (HERA). - Support to regional and local authorities on the instruments and services to effectively protect vulnerable populations e.g. those living with chronic diseases; investing in clear, timely and accessible public information on the phenomena linked to climate change and their effects on health; and involving and empowering citizens, including those most vulnerable, to take action locally. - Improve forecast and preparedness of extreme weather events e.g. heatwaves, as well as pollen counts, by further integrating the existing early warning systems and establishing real-time monitoring system for pollen, on the basis of new and well-functioning monitoring stations across Europe.	potential should be explored to monitor climate change hazards affecting health https://climate.copernicus.eu/ European Climate Adaptation Platform Climate-ADAPT, provides with Heat health action plans, https://bit.ly/38v6xQd European Climate Adaptation Platform Climate-ADAPT, provides with Green spaces and corridors in urban areas (if possible, non allergenic), https://bit.ly/3s1fo32 European Climate Adaptation Platform Climate-ADAPT, provides with models for European early warning systems, https://bit.ly/3MEH99v
3	(Air quality) Improve ambient air quality and reduce air pollution levels, including the exposure of the most vulnerable population.	 Full alignment with the latest WHO Air Quality Guidelines, as the ultimate authoritative document reflecting the latest scientific advancements in the study of air pollution and its effects on human health. Measures to mitigate the effect of air pollution on health, especially on vulnerable populations, including:	Adopt a health impact driven air quality index in the EU inspired by: the Canadian Air Quality Health Index https://weather.gc.ca/airquality/pages/index_e.html the US initiative AirNow https://www.airnow.gov/. The platform enables patients to monitor the air quality across the country, the wildfires and smoke and the impact on health (with tabs dedicated to asthma and heart diseases). The initiative includes educational programmes for schools and civil society organisations.
		for a long time are placed away from busy roads. The closer people stay for a long time to a busy road,	

		the greater the health risks, even if the air quality there meets the legal standards - Ensuring a distance of sensitive facilities like elderly homes, schools and hospitals also from livestock farms, as air quality around these also poses health risks. - Major gains can be made by substantially reducing ammonia emissions from livestock farms O Improve public information on air quality, both generally and in hot spots and densely populated areas. Access to accurate information on the levels of air pollution in real time is a valuable prevention factor, as it can help people adapt their daily activities to reduce their exposure. In particular: - Public information on air quality must be based on legal provisions and requirements clearly	
		 embedded in the EU air quality framework Information must be based on real-time measurements and include appropriate messaging targeted to vulnerable groups of the population, such as chronic respiratory patients. Existing EU-wide tools, such as the EU Air Quality Index and its application, must become better known through intensive promotion across the society; and also further elaborated to include 	
_	4 (Air quality) Tackle indoor air pollution through clear measurements, harmonised	pollution warnings and information tailored to vulnerable groups. There is an urgent need to address indoor air pollution and its related effects on respiratory health. Indoor air pollutants and allergens include mould, dust, tobacco	- 'Warmth and wellbeing pilot scheme', (2016-2019 - Ireland), which aimed to provide free, extensive energy efficiency upgrades to people living with lung disease, recognising the impact of indoor

	certifications, health-	smoke, heating/cooking emissions and volatile organic		environments on respiratory health and fighting disease inequalities
	relevant renovation	compounds (VOCs) generated by furniture, cleaning		by improving access to a safer environment
	programmes and funding	products and construction material. Coupled with poor		https://www.seai.ie/grants/home-energy-grants/free-upgrades-for-
	programmes and runding	·		
		ventilation , as we have witnessed during COVID, they are		eligible-homes/warmth-and-wellbeing/
		tightly linked with the development and increase of	-	'Bostadsanpassningsbidrag' (Sweden), a program run by local
		respiratory conditions, calling for cross-cutting policy		authorities composed of a housing adjustment grant for those with
		measures to address the resulting health burden.		a disability. It involved housing improvements such as remove the
				wall-to-wall-carpet or improve ventilation
		As one of the key aspects of the Green Deal, the EU aims to		https://www.boverket.se/sv/babhandboken/for-dig-som-
		accelerate the renovations of buildings , while reducing the		soker/vad-ar-bostadsanpassningsbidrag/
		overall emissions of the EU building stock through more	-	Green Ambulances (CRIPI – Belgium) Launched in 2000, the service
		energy-efficient buildings. However, the EU needs to also		aims to identify indoor pollution that may be the source of health
		address internal aspects such as the healthiness of indoor		problems. It is a non-medicalised intervention to promote healthy
		environments, and in particular indoor air quality. Drawing		living environments and it makes visible very well the connection
		from several national examples, the Commission must		between the environment and health (green cross)
		incorporate health-related criteria into the financial tools		https://environnement.brussels/thematiques/air-
		and mechanisms that will be deployed to support		interieur/depolluer-son-interieur/cripi
		renovation programmes across the region. This way, the EU	-	Finnish Indoor Air Programme (2018-2028) with the aim to support
		can also help reduce existing social inequalities, as a chronic		the work to overcome adverse health effects related to poor indoor
		respiratory disease will no longer impose a financial		air quality
		handicap to the patient.		https://helda.helsinki.fi/bitstream/handle/10138/313379/documen
				t 4.pdf?sequence=1
5	(Exposome) Further invest in	Extensive research is needed to identify balanced	-	The European Human Exposome Network (EHEN)
	exploring life-course	environments in which exposures allow development of		https://www.humanexposome.eu/. The world's largest network of
	exposures and addressing	immune tolerance/resilience, while avoiding sensitizing,		projects studying the impact of environmental exposure on human
	them to reduce the onset of	toxic (e.g. passive smoking, air pollutants), and other		health, from conception to death
	chronic non-communicable	adverse effects.	_	The European Human Biomonitoring project (HBM4EU)
	disease			https://www.hbm4eu.eu/. The project develops evidence on the
		The study of life-course exposures can offer insights on the		actual exposure of citizens to chemicals. It also provides for robust
		onset and progress of chronic respiratory conditions, and		interpretation of human biomonitoring data and the possible
		open ways towards a more preventative approach.		, and the post-will

		For example, by now it is common knowledge that genes alone cannot fully explain the origins of complex diseases such as allergy, asthma and COPD. Rather, it is a combination of genetic and environmental factors that can provide the full account, pointing towards a personalised approach in dealing with the disease. Furthermore, there is solid evidence that adult respiratory diseases almost always have their origins in early life.	impact of chemical exposure on human health, using the most up to date scientific tools
6	(Biodiversity hypothesis) Protection against the onset of allergy and asthma is linked to environmental microbial exposure in early life – the biodiversity hypothesis	The biodiversity hypothesis builds on the use of desensitization, as well as active early food introduction, may act on either allergic symptoms or lower respiratory viral infections preceding childhood asthma. - Farm- related protection is independently explained by farm-milk consumption and air-borne microbial exposure during early life. Farm dust holds great promise to prevent viral respiratory infections — an application with an enormous impact nowadays also outside the field of childhood asthma — for which the identification of active ingredients or their immune targets will be of paramount importance to implement the use of farm dust and its derivatives. - A rich commensal flora is essential for the maturation of the neonatal immune system. The microbial composition is influenced by our diet and farm-milk may promote its richness. Many studies have pointed out that these microbes can profoundly modify host immune responses at different levels,	Early environmental, natural, exposure protect via active immune regulation of allergic responsiveness, as a side-effect necessary for parasite survival. There are two major approaches tested or being tested to date: 1. Population intervention such as the Finnish Allergy and Asthma Programme (2008-2018), which embraces health and reduces medicalization of allergy, through the promotion of rich diets and contacts with nature (https://pubmed.ncbi.nlm.nih.gov/33965232/). The programme built on the previous successful Finnish Asthma Programme. 2. The best real-life example testing the biodiversity hypothesis has just commenced in the city of Lahti (EU Green Capital 2021, Natural Step – Lahti Regional Health and Environment Programme 2022-2032). https://drive.google.com/file/d/1kHL7qZnh-yYAObXFlqol7rhuyyq7raok/view. Not only the chronic respiratory disease, asthma, but also diabetes, obesity and depression are included. Both public health and environmental goals have been set for food, exercise/mobility, housing, and nature contacts. https://paijat-sote.fi/wp-

		and in parallel influence the lung barrier and their	<pre>content/uploads/2021/11/luontoaskel_terveyteen-</pre>
		responsiveness to external triggers.	<u>ohjelma_final.pdf</u>
			3. Novel exposure mechanisms and therapies to reduce the
			prevalence of asthma such as the research of the A World
			Without Asthma international consortium (AWWA). It focuses
			on three domains to reveal novel mechanisms to prevent
			asthma, based on epidemiological findings in areas where
			prevalence of childhood asthma is still low
			(https://www.lumc.nl/org/parasitologie/research/awwa/). This
			includes:
			- the impact of farm milk on microbiome and immune
			maturation in early life (diet-mediated microbial richness)
			- the role of farm dust in protection against lower viral
			respiratory tract infections, and
			- the role of immunomodulatory molecules secreted by
			evolutionary conserved commensals, i.e. helminths
			(https://www.lumc.nl/org/parasitologie/medewerkers/her
			melijnsmits)
7	(Tobacco control)	By addressing commercial determinants of (novel) tobacco	- WHO Framework Convention on Tobacco Control (FCTC)
	Expand the legal provisions	and related products, the EU can tackle industry practices	https://www.who.int/fctc/text_download/en/
	for advertisement and	used to make them more attractive to consumers, especially	- European Commission report on the application of the Directive
	flavorings of conventional	the youth. Overall, the Commission must s trengthen the	2014/40/EU concerning the manufacture, presentation and sale of
	tobacco to also cover novel	rules on conventional tobacco products and also adapt the	tobacco and related products 2021, https://bit.ly/3y7XLm9. To
	tobacco and related	legal provisions on packaging and labelling requirements to	date, eight EU Member States have exercised their right to
	products	also cover e-cigarettes and novel products. Measures must	implement plain packaging in tobacco products: Belgium, Denmark,
	products	also include:	France, Hungary, Ireland, the Netherlands, Slovenia, the UK (still an
		- Harmonise rules by prohibiting industry practices	EU Member States when the measure was taken). Commission
		such as characterizing flavours and colouring	report & support study
		(including in e-cigarettes and roll-your-own tobacco)	- The MPOWER measures (WHO) are intended to assist in the
		aimed at rendering smoking more attractive,	country-level implementation of effective interventions to reduce
		especially towards young populations	country level implementation of effective interventions to reduce
		especially towards young populations	

		- Adopt mandatory plain packaging in the EU, drawing from the evidence coming from countries that have adopted this measure, suggesting that it reduces the appeal of smoking, and contributes to the reduction of smoking prevalence		the demand for tobacco, contained in the WHO FCTC https://www.who.int/initiatives/mpower
8	(Smoking) Expand tobacco cessation programmes encouraging multidisciplinary team, and accessible quitting treatments and techniques; expand smoke-free environments in line with the Framework Convention on Tobacco Control (FCTC); ensure greater compliance with national laws for nonsmoking spaces; expand the EU Tobacco Products Directive restrictions to novel tobacco and related products	Acknowledging the risks posed by smoking, several EU Member-States have moved to adopt policies that aim at significant decreases in smoking rates among the population over the coming years. In the context of its role to preserve public health, the EU must take steps to ensure the achievement of its goal for a tobacco-free generation by 2040, as stated in its ambitious Beating Cancer Plan. Of course, tackling tobacco smoke bears benefits not only for cancer, but for other disease areas too, including chronic respiratory conditions such as asthma and COPD. To reduce the effects of smoking in the population the EU should: - Encourage the adoption of robust tobacco cessation programmes offer the specialist support and access to smoking cessation therapy free of charge for smokers - Advance EU legislation towards smoke-free environments such as shools and hospitals surroundings, transport stops, parcs, restauration terrasses.	-	Strategy for a smoke free generation, 2022-2028 (Belgium), which aims by 2040 to reduce the number of daily smokers among the over 15 years to less than 5%, while for young people the target is 0% or close to 0% https://bit.ly/38SM1t1 Tobacco-free Finland 2030 has a goal of achieving less than five per cent of the adult population consuming tobacco or nicotine products on a daily basis. https://savutonsuomi.fi/en/ Tobacco Free Ireland 2025 sets a target for Ireland to have a smoking prevalence rate of less than 5% by 2025, effectively making the country a tobacco free society https://www.gov.ie/en/policy-information/5df1e7-tobacco-free-ireland/ French national programme "The fight against tobacco 2018-2022" has an ambition of reaching the first generation of non-smoking adults by 2032 https://solidarites-sante.gouv.fr/IMG/pdf/180702-pnlt_def.pdf Smoke-free generation 2035 (the Netherlands) aims to ensure that children who were born in 2017 and will be 18 years old by then to grow up tobacco-free https://www.loc.gov/item/global-legal-monitor/2019-09-25/sweden-new-rules-on-smoking-in-public-places-and-sale-of-25/sweden-new-rules-on-smoking-in-public-places-and-sale-of-25/sweden-new-rules-on-smoking-in-public-places-and-sale-of-25/sweden-new-rules-on-smoking-in-public-places-and-sale-of-25/sweden-new-rules-on-smoking-in-public-places-and-sale-of-25/sweden-new-rules-on-smoking-in-public-places-and-sale-of-25/sweden-new-rules-on-smoking-in-public-places-and-sale-of-25/sweden-new-rules-on-smoking-in-public-places-and-sale-of-25/sweden-new-rules-on-smoking-in-public-places-and-sale-of-25/sweden-new-rules-on-smoking-in-public-places-and-sale-of-25/sweden-new-rules-on-smoking-in-public-places-and-sale-of-25/sweden-new-rules-on-smoking-in-public-places
9	(Food products) Harmonise Precautionary Allergen Labelling through the establishment of allergen	EFA considers allergen labelling as a food safety issue. While often downplayed, food allergy is a common and potentially life-threatening disease. It represents a significant burden for patients' health, as exposure to a food	-	tobacco-enter-into-force/ European Federation of Allergy and Airways Diseases Patients' Associations (EFA) – FoodDetectives report: Quality of Life for People with Food Allergies in Europe – A Menu for Improvement https://www.efanet.org/images/EFA FoodDetectives Report.pdf.

thresholds; undertake allergenicity risk assessment of all novel foods entering the EU market; and ensure close monitoring of emerging food allergens e.g. chickpeas, lentils.

allergen has consequences that range from a mild allergic reaction to an extremely dangerous anaphylaxis event. In addition, food allergy also leads to social, emotional and economic costs, affecting patients' quality of life as a whole. When it comes to food choices, food allergy patients face risks related to food labelling on a daily basis. To protect millions of patients from the health risks posed by food allergy, EFA identifies three main areas where EU action would be urgent:

- PAL is a voluntary type of labelling used by manufacturers to indicate potential unintended allergen presence in food due to cross-contact in the production cycle. PAL statements can be in various forms e.g. 'may contain...', 'may contain traces of...' etc. The lack of a harmonised approach in Europe has led to an inconsistent but also excessive use of PAL. As a result, consumers with food allergy are confused and lose trust on labelling, often experiencing fear and anxiety when deciding about their food. EFA calls for a harmonised PAL through the establishment of allergen thresholds, on the basis of a Quantitative Risk Assessment (QRA). To this end, the European Commission must support related research and, on that basis, adopt common rules applicable across the EU.
- Amid fast-moving global trends in food systems, new consumption patterns and food process methods arise in a rapid pace. The consumption of novel foods such as is increasingly entering the EU market. However, novel foods such as insects and certain agricultural products might contain ingredients that are allergenic to conssumers. The Commission must

- The report takes stock of the implementation of the EU Food Information Regulation 1169/2011 in the EU and provides recommendations on how to address existing policy gaps related to food allergen labelling, including Precautionary Allergen Labelling.
- European Federation of Allergy and Airways Diseases Patients'
 Associations (EFA) Statement to the consultation on the revision
 of EU legislation on Food Information to Consumers, 2022
 https://www.efanet.org/images/2022/EFA_PAL_statement_March_2022.pdf
- Voluntary Incidental Trace Allergen Labelling (VITAL) Program
 https://vital.allergenbureau.net/. An initiative of the Allergen
 Bureau, a cooperation established in 2005 in Australia and New
 Zealand consisting of food industry, national and multi-national
 food manufacturing and marketing companies, suppliers,
 importers, exporters, retailers, consumer groups and health
 professionals. The VITAL program has established a set of reference
 doses to guide the use of PAL by food manufacturers..
- Integrated Approaches to Food Allergen and Allergy Risk
 Management (iFAAM) project (2013-2017), aiming to develop
 evidence-based approaches and tools for the management of
 allergens in food and integrate knowledge derived from their
 application, including in the use of PAL. Final report:
 https://cordis.europa.eu/docs/results/312/312147/final1-ifaam-final-report-ver-6.pdf
- International Life Sciences Institute Europe (ILSI Europe),
 organising research activities on food allergy, including:
 - 'Can we Define a Level of Protection for Allergic Consumers that Everyone can Accept?', 2020, https://www.sciencedirect.com/science/article/pii/S027323002
 030177X

		ensure the safety of all novel foods entering the EU	2) 'Are Current Analytical Methods Suitable to Verify VITAL®
		market before they do so, through the continuous	2.0/3.0 Allergen Reference Doses for EU Allergens in Foods?',
		empowerment of EFSA to undertake allergenicity	2020,
		risk assessments. Where applicable, risk	https://www.sciencedirect.com/science/article/pii/S027869152
		assessments must provide recommendations for	<u>0305998?via%3Dihub</u>
		appropriate allergen labelling, in order to ensure	3) 'Allergen quantitative risk assessment within food operations:
		information of consumers.	Concepts towards development of practical guidance based on
		- Ensure close monitoring of evidence arising from	an ILSI Europe workshop', 2022, https://ilsi.eu/wp-
		emerging food allergens (foods already widely	content/uploads/sites/3/2022/04/1-s2.0-S0956713522001104-
		consumed among the population, such as chickpeas	<u>main.pdf</u>
		and lentils) with a view to facilitating their	- Food and Agriculture Organisation (FAO), Thinking about the
		introduction to the EU list of common allergenic	Future of Food Safety: A Foresight Report, 2022,
		foods, where necessary	https://www.fao.org/3/cb8667en/cb8667en.pdf
			- European Food Safety Authority (EFSA) webpage on novel foods
			https://www.efsa.europa.eu/en/topics/topic/novel-food
			- L. Soller et al. 'Allergic reactions to emerging food allergens in
			Canadian children', 2021,
			https://aacijournal.biomedcentral.com/articles/10.1186/s13223-
			<u>021-00573-y</u>
10	, ,	Nany non-food consumer products, including clothing,	- European Federation of Allergy and Airways Diseases Patients'
	proper (on-pack) allergen	osmetics, toys, biocides, cleaning, hygiene and construction	Associations (EFA) – EFA response to public consultation on
	labelling in non-food	roducts, contain chemical substances and agents that may	fragrance allergen labelling, 2020,
	consumer products	ritate the respiratory system and airways of users.	https://www.efanet.org/news/3856-efa-response-to-public-
			consultation-on-fragrance-allergen-labelling
		abelling information on the presence of allergens in non-food	- European Federation of Allergy and Airways Diseases Patients'
		onsumer products is important for people with respiratory	Associations (EFA) – EFA response to the revision of the EU
		liseases such as allergy and asthma, as well as skin	Construction Products Regulation, 2020,
		ensitivities such as atopic dermatitis (eczema).	https://www.efanet.org/images/2022/CPR_review_EFA.pdf

Please list up to ten suggestions and be as specific as possible. You may provide a short clarification on why these suggestions rank high and add relevant links (e.g. scientific literature, reports of reference institutions, policy documents).

Please indicate if the action has been evaluated or piloted, whether there is information on (cost/effectiveness, or why it should be tried as a novel option with high impact.

3. What could be **role of stakeholders** for achieving the priorities, and the actions that the stakeholders can do in collaboration with public health authorities and other parties?

Please list up to five suggestions and be as specific as possible.

You may provide a short clarification on why these suggestions rank high and add relevant links (e.g. scientific literature, reports of reference institutions, policy documents).

	Roles	Rationale	References	Other concerned parties
1	Patient centered policy/action: Codesigners of policy and/or action	Engaging, integrating, and finding out the real needs of the patient communities (patient evidence) at EU, national and local levels. Bottom-up approach	https://www.efanet.org/about- efa/organisation/members	Citizen organisations with expertise on minorities, socially disadvantaged, and migrants. Healthcare professionals (multidisciplinary approach). Environmental (health) organisations.
2	Priority setting: Advisers	Targeted groups acting as advisers at all policy-making and decision-making levels to ensure citizens/patient centered policy/action	https://www.efanet.org/about-efa/organisation/members https://www.efanet.org/about-efa/partnerships	Healthcare Professionals Any other stakeholder group that can have impact on the result
3	Partnership and sustainability: Connectors to their	Two-way connecting policy makers and authorities to grassroots for commitment	European Lung Health Group www.breathevision.eu	Multistakeholders

	communities and builders of alliances and consensus	and sustainability and building and maintaining in a neutral way multistakeholder alliances	https://www.efanet.org/about- efa/organisation/members https://www.efanet.org/about- efa/partnerships	
4	Leadership: Developers and leaders of targeted action to their communities	Best placed to develop and take leadership on patient information, education, empowerment provided they receive the resources to do so	Finnish Asthma and Allergy programmes: specific actions led by organisations who are concerned by the action; patient organisations public awareness, patient information and evidence, education https://www.efanet.org/about-efa/organisation/members https://www.efanet.org/about-efa/partnerships	Multistakeholder
5	Communication: Implementers of information, tools, dissemination to their communities and capacity building	Direct reach, channels, narrative (science and policy => lay public), awareness and capacity building to, and knowledge of the target groups who are affected in a specific way	https://www.efanet.org/inform/expert-patient-network/3996-efa-capacity-building https://www.efanet.org/about-efa/organisation/members	

Chronic respiratory diseases

4. Please indicate your **priorities for EU-supported action** in this strand.

Please select up to five priorities and be as specific as possible.

You may provide a short clarification on why these priorities rank high and add relevant links (e.g. scientific literature, reports of reference institutions, policy documents).

	Priorities	Rationale	References
1	(Diagnosis) Urgently increase the	Chronic obstructive pulmonary disease (COPD)	- Chronic obstructive pulmonary disease (COPD) and asthma are the
	implementation of chronic respiratory	ranked in 2019 as the 3 rd cause of death	two largest contributors to global respiratory disease burden.
	disease screening and early detection	worldwide and among the top 10 leading to	Global Burden of Disease Study 2021,
	programmes at national level	premature deaths and disability. Asthma and	https://www.thelancet.com/pb-
		COPD are keys driver of disease burden and	assets/Lancet/gbd/summaries/diseases/chronic-respiratory-
		the general health status of a person.	<u>diseases.pdf</u>
		Early diagnosis is fundamental to delay	- The WHO NCD Framework aims at reducing by 25% deaths from
		disease progression and save lives and direct	chronic respiratory disease by 2025.
		and indirect costs. Timely diagnosis can only	https://www.euro.who.int/en/health-topics/noncommunicable-
		be achieved through robust determination	diseases/chronic-respiratory-diseases/publications/2016/action-
		and healthcare system's anchored lung	plan-for-the-prevention-and-control-of-noncommunicable-
		disease screening and early detection	diseases-in-the-who-european-region-20162025
		programmes.	
2	(Standards of care) Implement	Allergy and airways diseases are complex	- European Respiratory Society White Lung Book
	standards of care for chronic	disease, with a huge burden, that are	https://www.erswhitebook.org/chapters/chronic-obstructive-
	respiratory disease, using the full	irreversible in the case of COPD. However, the	pulmonary-disease/
	potential of multi-disciplinary teams	attention from healthcare systems seems	- Prioritised research agenda for prevention and control of chronic
	and Integrated Care Models to	insufficient considering their morbidity, social	respiratory diseases (2010,
	embrace patients' health needs – Link	burden, and morbidity. Allergy and airways	https://erj.ersjournals.com/content/36/5/995)
	the chronic respiratory disease strand	diseases tend to appear together and share	- BREATHE Vision 2030 (2020, European Lung Health Group,
	with the mental health strand and the	many interlinks. Asthma and COPD are linked	https://www.breathevision.eu/vision-2030)
	cardiovascular strand	with other chronic diseases that contribute	- Chronic obstructive pulmonary disease (COPD) and comorbidities
		to the overall severity and manifestations of	(study from Croatia 2015, 90% of COPD patients had comorbidities
		the disease. The most common comorbidities	https://erj.ersjournals.com/content/46/suppl_59/PA1123
		in COPD are ischaemic heart disease, anxiety	
		and depression, osteoporosis, skeletal muscle	

	dysfunction, gastro-oesophageal reflux, anaemia, lung cancer, diabetes and metabolic syndrome. Despite these facts, many of the issues that were asked to be a priority on allergy and airways diseases a decade ago are far from being solved. The European Lung	- Chronic obstructive pulmonary disease (COPD and depression (study from Madrid 2017, https://erj.ersjournals.com/content/50/suppl 61/PA945)
	Health Group has launched the BREATHE	
	Vision 2030 with the priorities towards better awareness, prevention, care, and research	
	for this decade.	
3 (Best quality care) Reduce disease	It is paramount that patients receive the care	The cost of COPD exacerbations in Denmark.
exacerbations and hospitalisations	but also the knowledge they need to cope	The <u>days lost</u> due to allergic rhinitis in Europe.
due to allergy, asthma and COPD	with their disease. Patients should be given	The <u>sick days</u> on average due to severe atopic eczema patients in Europe.
through better self-management and	basic tools such as written management plans	
rehabilitation	and therapeutic education to understand	
	their disease and address it in a way they can	
	live their lives to the full.	
4 (Digital health) Promote digital health	Allergy, asthma and COPD being all of the	Perspectives of patients and healthcare professionals on mHealth for
literacy and increase patient access to	chronic diseases represent a good opportunity	asthma self-management (data from myAirCoach project 2017,
digital tools to support the	to test digital health in a real environment.	https://erj.ersjournals.com/content/49/5/1601966)
management of their disease	Not only these diseases require	
	multidisciplinary management, but also they	
	interlink between the patient status and	
	their external exposure, their symptoms and	
	how they treat them. Digital health brings a	
	great opportunity to improve a sustained	
	doctor-patient relationship digitally, empower patients to be on top of their diseases and	
	generate the currently missing data on these	
	diseases.	

5	(Prevention) Tackle the increasir prevalence of childhood chronic allergy an airways disease	•	Nationwide Programmes for asthma, allergic disorders and COPD have shown remarkable improvements in prevention and overall management with major cost savings, both for the patients and society. These conditions are examples of NCDs and may pave the way to significant change of managing all these diseases as they share common features like microbial imbalance (dysbiosis), long-term immune dysfunction and lowgrade inflammation. - Population intervention such as the Finnish Allergy and Asthma Programme (2008-2018), which embraces health and reduces medicalization of allergy, through the promotion of rich diets and contacts with nature (https://pubmed.ncbi.nlm.nih.gov/33965232/). The programme built on the previous successful Finnish Asthma Programme.				
ei Pi Yo do Pi	5. Please provide your selection of effective policies, best practices, promising approaches and innovative actions (to be put for consideration of Member States) to effectively address the priorities. Please list up to ten suggestions and be as specific as possible. You may provide a short clarification on why these suggestions rank high and add relevant links (e.g. scientific literature, reports of reference institutions, policy documents). Please indicate if the action has been evaluated or piloted, whether there is information on (cost-)effectiveness, or why it should be tried as a novel option with high impact.						
	Effective policies, best practices, promising approaches or innovative actions	Rationale	References				

1	(Disease prevention) Run comprehensive lung screening programmes for people at risk of chronic obstructive pulmonary disease (COPD) and add value to existing lung cancer screening programmes given the commonalities of both diseases and risk factors.
2	(Early diagnosis) Invest in asthma and COPD screening at primary care (i.e. COPD risk-determining questionnaires and spirometry) and on early allergic rhinitis diagnosis through the wider healthcare system

Screening serves to increase early detection, timely diagnosis and treatment, and results in reduced mortality.

Interventions to increase and improve diagnosis should focus on:

- including people at risk of COPD in existing lung cancer screening programmes
- systematic COPD screening questionnaires among smokers
- early detection programmes for asthma and COPD at primary care
- <u>UK community-based Lung Health Checks</u> (LHC, University of Manchester national trial) is a nurse-led programme targeting high-risk smokers in deprived areas. Preliminary results show a calculation of lung cancer risk, higher diagnosis of other chronic and rare lung diseases, and <u>increased</u> <u>smoking cessation rates</u>.
- Results from the <u>USA National Screening Trial</u> (NLST) showed a 20% decrease in lung cancer mortality but also that the <u>benefits</u> are greater when the screening targets those with normal lung function or only mild-to-moderate COPD. Research shows an <u>interplay</u> between the airflow obstruction present in lung cancer and in COPD.
- Screening pilots being conducted in the EU such as in Belgium and the Netherlands (NELSON trial).

Primary care is the entry point for patients with a main task of filtering health needs into the healthcare system. As chronic respiratory diseases, asthma and COPD are firstly supected at primary care but there is still a high level of underdiagnosis and misdiagnosis due to:

• lack of systematic screening questionnaire

- lack of systematic screening questionnaires among the population at risk of chronic respiratory disease
- no use of diagnostic tools or poor diagnostic sensitivity
- patient underreporting symptoms that could be improved through more awareness of the disease
- poor socioeconomic status

Pharmacists play an important role in supporting patients with respiratory allergies, particularly for over-the-counter advice to treat mild allergic rhinitis.

Early detection of COPD:

- Promising approach: The UK has developed a COPD prognostic model based on case-finding in primary care (<u>BLISS Research Programme</u> and cluster Randomised Controlled Trial)
- The Dutch National Lung Alliance (LAN) and the Lung Foundation (LongFonds) have adopted a COPD screening 8 item questionnaire (COPD Risicotest)

Timely diagnosis of asthma:

- Likelihood of under-diagnosis of asthma and main and basic recommendation from 2019 to accompany clinical diagnosis with objective testing to improve diagnosis in Europe (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6481983/)
- Eactors associated with poor diagnosis of asthma, data from F
- Factors associated with poor diagnosis of asthma, data from EU countries 2018 (https://www.atsjournals.org/doi/10.1164/rccm.201804-0682CI)

Early diagnosis of allergy:

	T		
		When properly trained, they are fundamental in	The role of pharmacists according to ARIA Guideline in early diagnosis and
		recognising allergic rhinitis and in motivating	management of allergic rhinitis (AIRWAYS ICP project)
		patients to consult a doctor.	
3	(Multidisciplinary care) Re-organise the delivery of healthcare for severe chronic respiratory disease patients through multidisciplinary teams integrating the patients needs across primary, secondary and tertiary care that embrace the patients health status holistically.	Allergy and airways diseases are not only interlinked conditions, but also diseases with a high degree of co-morbidities. Care delivered in a fragmented or siloed way impacts on the success indicators. EFA patients calls for care models for severe patients that are structured in multidisciplinary teams. Such an endeavor entails: • Better harmonized curriculums and training to increase the number of health professionals in underserved specialisations (i.e allergology) • Curriculum and training on allergy and airways diseases for clinicians, paediatricians and general practitioners • More specialized nurses to integrate allergology, dermatology and respiratory teams, providing care and patient education • Mental health care in advance stages of COPD is crucial for patients as they are at high risk of depression, is a prevalent disorder in COPD patients and frequently it is not diagnosed and not treated.	Patient-driven recommendations to improve standards of care across Europe for COPD (EFA Minimum Standards of Care, 2013, https://efanet.org/news/2278-97press-release-efa-s-new-book-on-minimum-standards-of-copd-care). Need for more professional and service integration for the management of COPD was found in EU project WELCOME (https://erj.ersjournals.com/content/44/Suppl 58/P4739) Respiratory nurse practitioners play an important role in ICU management, disease control, patient education, self-management and emergency room management: • Community nurse-led management of COPD in Italy improved smoking cessation, BMI, physical activity and vaccination indicators in 2016 (https://pubmed.ncbi.nlm.nih.gov/34783318/) • Nurses being trained to empower COPD patients to self-manage, example from Portugal https://erj.ersjournals.com/content/56/suppl_64/5172 • Demonstrated role of dermatology nurses in atopic eczema (implemented in UMC Utrecht in the Netherlands). Inclusion of tertiary care into the management of COPD such as pulmonary rehabilitation (see 5), physical exercise programmes and especially psychological support and care: • Mental health with respiratory is the issue where European patients consider that public authorities are putting less attention (2019 EFA Patients ACCESS repor p32.,

			https://efanet.org/images/ShowLeadership/Report-Showleadership_FINAL.pdf) • Evidence from Italy confirms COPD patients see mental health as an unmet need: https://erj.ersjournals.com/content/50/suppl_61/PA2584 • 1 in 3 COPD patients suffer from depression (2020 UK population based study: https://erj.ersjournals.com/content/56/suppl_64/5181)
4	(Integrated Care Models) Improve the predictability, admission to the emergency room and in-patient and out- patient care for chronic respiratory disease exacerbations and introduce Integrated Care Models	Advanced staged COPD patients are more likely to enter the emergency room, an experience that might impact their general health status beyond their lung function. The prospect of providing healthcare also at home has been proved satisfactory for the patients and their carers and also cost-effective, as it helps reducing hospitalization days and reduce emergency room visits.	 Example for in-patient COPD care: The Dutch care path for COPD (COPD Zorgpad) has been implemented since 2019 and describes the care during and after hospitalization for COPD patients who have had an exacerbation. The main objective is to reduce hospital admission days due to COPD, as well as improved quality of life and patient satisfaction. Continuity of care, listening to the needs of the patient and good interdisciplinary collaboration are required to achieve this. The patient can also become the coordinator of his own care plan. (https://www.longaanval.nl/inhoud-zorgpad/) Examples of home care COPD pilots in Poland (https://pubmed.ncbi.nlm.nih.gov/31002103/), Spain Mallorca (https://erj.ersjournals.com/content/58/suppl 65/PA3823), Spain Madrid (https://erj.ersjournals.com/content/48/suppl 60/PA3789) Examples of atopic kindergartens and schools in several Swedish municipalities and linked to the Swedish Discrimination Act approved in 2015 in Umea, Malmo, Rattvik.
5	(Pulmonary rehabilitation) Increase the accessibility to multi-disciplinary	Pulmonary rehabilitation is a fundamental component of the integrated disease management of chronic respiratory disease patients. It is a	The content of pulmonary rehabilitation programmes as well as the healthcare professionals involved can be adapted (review from 2014 https://erj.ersjournals.com/content/43/5/1326)

	rehabilitation centers especially after chronic respiratory disease exacerbation to ensure the continuum of good quality care	comprehensive intervention based on thorough patient assessment followed by patient-tailored therapies that include, but are not limited to, exercise training, education and behaviour change. Pulmonary rehabilitation has consistently shown that individuals with chronic respiratory disease experience: a decrease in daily symptoms of dyspnoea, fatigue, anxiety and depression; improvements in exercise performance, self-efficacy and health status; and a decrease in healthcare utilization. From a patient perspective: • There should be an increase on the number of physiotherapists trained on pulmonary rehabilitation • Pulmonary rehabilitation should be offered (and accessible) to any asthma and COPD patient who has suffered an exacerbation, including online	The European Respiratory Society has developed HERMES, with a professional curriculum for respiratory physiotherapists (https://breathe.ersjournals.com/content/breathe/15/2/110.full.pdf) There are already innovative successful approaches to multidisciplinary centered around pulmonary rehabilitation like CIRO, a center located in Horn (the Netherlands) specialised in treating patients with chronic lung diseases, heart failure or sleep-related respiratory distress. Treatment is personalised to the patient and they can be interned, do a 14-week stage, or come in on a consultation basis. They report many success with their multidisciplinary approach. https://www.ciro-horn.nl/nl There are independent programmes such as "Living well with COPD", a successful pulmonary rehabilitation Canadian programme that was implemented in the United Kingdom (https://www.livingwellwithcopd.com/living-well-and-pulmonary-rehabilitation.html) and evaluated (2013, https://bmcpulmmed.biomedcentral.com/articles/10.1186/1471-2466-13-50#Sec25) Rehabilitation of damaged airways can also be combined with the use of novel medical devices such as PulseHaler airway opener (EU funded project to end 2022) Tele-rehabilitation has shown to reach similar indicators than in-person rehabilitation, example from Greece (https://eri.ersjournals.com/content/49/5/1602129),
6	(Self-management) Every Member State should encourage and measure the effective establishment of national registries and written	It is disconcerting that one in three asthma and COPD patients do not feel involved in decisions towards their therapy. Less than half of patients have a written management plan and, even worse, many patients with	Full patient perspective around written management plans in patient-driven survey on asthma and COPD written management plans (2019 EFA Patients ACCESS report p35, https://efanet.org/images/ShowLeadership/Report-Showleadership FINAL.pdf) Self-management plans for asthma:

action and management
plans to every allergy,
asthma and COPD patient.

COPD (33%) and asthma (20%) indicate that they have "never heard about" written management plans.

Plans guide patients to take measures to improve adherence and treatment technique through systematic patient education all along the disease pathway

• Establish Disease Management **Programmes for asthma and COPD**, with specific patient curricula and management plans, and with measurement tools (to avoid the limited evaluation occurring in Germany, 2020:

https://pubmed.ncbi.nlm.nih.gov/32143231/

Establish disease specific patient registries, especially targeting the most severe, and electronically

- Asthma Society of Ireland, asthma self management plan (https://www.asthma.ie/about-asthma/learn-about-asthma/managingyour-asthma/asthma-action-plan)
- Clinicians recommendations for self-management for asthma (2015 https://breathe.ersjournals.com/content/11/2/98)
- Danish Severe Asthma Registry and self-management electronically (https://pubmed.ncbi.nlm.nih.gov/33209214/)
- Information can also be 27synchronized and channeled via eHealth and mHealth tools that facilitate self-management of diseases, such as the connected inhaler of MyAirCoach https://cordis.europa.eu/project/id/643607/reporting

Self-management plans for COPD:

- Time for a longer and better life for patients with COPD (2017, European studies, https://erj.ersjournals.com/content/51/1/1702569)
- German Disease Management Programme VENTO, Germany (2019, https://erj.ersjournals.com/content/54/suppl 63/PA714)
- COPD patients need more information about self-management: a crosssectional study in Swedish primary care (2019, https://pubmed.ncbi.nlm.nih.gov/31694439/)
- COPD action plan developed by the Dutch Long Alliance in collaboration with patient group LongFonds (https://bestellen.longfonds.nl/product/longaanval-actieplan-copd/)
- There is very diverse evidence on the reasons why self-management might be successful among only a percentage of COPD patients and the topic requires further research (https://erj.ersjournals.com/content/48/1/6) and characteristics of effective self-management interventions in patients with COPD: individual patient data meta-analysis (2016, https://erj.ersjournals.com/content/48/1/55#sec-8)

	education through programmes and spaces that embrace their needs and through e-learning courses related to prevention and treatment and peer support groups	empower the patient to be at the center of its care. It provides with the basis to understand the disease, scoping for symptoms, self-management and the different treatment techniques. Therapeutic education should be addressed to patients but also to parents and carers. To be successful, it is important to: • Ensure there are personal management plans in place	 (https://erj.ersjournals.com/content/54/suppl_63/PA931) Atopic eczema schools have been created in several EU countries to provide atopic dermatitis patietns with education on diseae management. Examples from: Germany, (https://pubmed.ncbi.nlm.nih.gov/30217280/), France (https://pubmed.ncbi.nlm.nih.gov/23406346/), Spain (school for parents, https://dialnet.unirioja.es/servlet/articulo?codigo=8259365). COPD education: inhaler technique long term education in the Netherlands (https://erj.ersjournals.com/content/54/suppl_63/PA1479)
		 Provide with opportunities to access patient education at any time (especially digitally) Multiply and improve training options for patients to improve inhaler techniques (from doctor to pharmacist) 	and through videos (https://erj.ersjournals.com/content/54/suppl 61/PA3940) or through cards (https://erj.ersjournals.com/content/50/suppl 61/PA3940) or through cards (<a "="" astmaoallergiforbundet.se="" din-forening="" href="https://erj.ersjournals.com/content/48/suppl 60/PA5006) - Peer support: patient-led camps for children and adults in Sweden (https://astmaoallergiforbundet.se/medlem/din-forening/), exercise classes and singing groups for COPD patients in Ireland (https://copd.ie/support-groups/), disease specific classes in Denmark (https://www.astma-allergi.dk/aktiviteter/kurser/).
8	(Digital health) Enable basic tele-health and more advanced tele-monitoring of chronic diseases using digital tools and devices to measure lung function and allerginicity	According to a pan-European survey conducted by EFA in 2021 and to be published in June 2022 (upcoming DIG IT report), asthma and COPD patients are open and willing to use digital health, provided they have access to patient-friendly tailored tools and to the education/training to use them. Digital health for chronic respiratory disease is possible, but it needs to be adapted to the patients'	National tele-health services: - E-pulse application (Turkey), is the Turkish national e-Health service hub launched in 2015. From a patient perspective it is very practical as it not only works as a hub for the patients' medical records, but it is also managed by the patient (who is then in contact with healthcare professionals through the app) and interestingly includes options for emergency care, such as calling an ambulance (i.e. in

needs and demographics:

- For asthma, playful solutions that invite

younger patients and carers to share information and master their disease, and

case of anaphylaxis). The app locates the patient via their mobile

phone signal and assigns the nearest ambulance. In that case, the

emergency note can be viewed by the ambulance staff even before

reaching the patient. For example, if the patient has a severe allergy

- adult applications to especially help those with severe forms of the disease
- For COPD, older age friendly interface and tools that help patients cope with their disease and do not create any extra burden
- For allergies, digital applications that support patients taking decisions about their exposure to allergens, to monitor their symptoms and link them with external indicators such as pollen, air quality and food ingredients.
- to specific medication. The system is also integrated to other official procedures like preparing ID for a new born, getting health or disability reports online.
- The **Danish TELEKAT pilot** seeks to develop a preventive home monitoring concept across sectors for chronic obstructive pulmonary disease (COPD) patients. The concept of the TELEKAT project is to reduce admissions by enabling the COPD patients to conduct self-monitoring and maintain rehabilitation activities in their own home. (2012,
 - https://pubmed.ncbi.nlm.nih.gov/23020647/)
- The Danish Severe Asthma Register (DSAR) works as an electronic patient record and aims to be a working tool for diagnosis and management with patient in biological treatment (2020, https://erj.ersjournals.com/content/56/suppl 64/1354)

Monitoring applications need to be adapted to the patients' demographics, like the following:

- Luchtbrug (airlift in English) is an digital monitoring app created in 2010 and addressed to children with Asthma that is being used in 20 hospitals in the Netherlands with the aim of reducing hospital visits and improving asthma control (https://www.luchtbrug.nl/)
- Automated telephone message service for people with uncontrolled asthma or COPD (results 2020 United Kingdom)
 https://erj.ersjournals.com/content/56/suppl_64/107

Digital monitoring devices:

- iCase portable oximeter (EU funded project ended 2019)
- ConneCare <u>learnings</u> for an integratd care app (EU funded project ended <u>2019</u>)

9	(Repair) Advanced	Recent advances with techniques that allow for the	•	Use	of	'organoids'	to	repair	lung	tissue
	scientific research and	creation of 'mini-lungs' allow researchers to carry out		(https:	://pubm	ed.ncbi.nlm.nih.	gov/315	50983/		and
	development towards a	experiments that can tell us how to switch lung cells		https:/	//www.r	ncbi.nlm.nih.gov	/pmc/art	ticles/PMC	C6376275/)	
	CURE for allergy and	to a state where they will repair the lungs. These								
	airways diseases	advances also mean that effective lung regeneration								
		is within reach.								

6. What could be **role of stakeholders** for achieving the priorities, and the actions that the stakeholders can/should lead and can/should do in collaboration with public health authorities?

Please list up to five suggestions and be as specific as possible.

You may provide a short clarification on why these suggestions rank high and add relevant links (e.g. scientific literature, reports of reference institutions, policy documents).

	Roles	Rationale	References	Other concerned parties
1	Patient centered policy/action: Codesigners of policy and/or action	Engaging, integrating, and finding out the real needs of the patient communities (patient evidence) at EU, national and local levels. Bottomup approach	https://www.efanet.org/about- efa/organisation/members	Citizen organisations with expertise on minorities, socially disadvantaged, and migrants. Healthcare professionals (multidisciplinary approach). Environmental (health) organisations.
2	Priority setting: Advisers	Targeted groups acting as advisers at all policy-making and decision-making levels to ensure	https://www.efanet.org/about- efa/organisation/members	HCPs Any other stakeholder group that can have impact on the result

		citizens/patient centered policy/action	https://www.efanet.org/about- efa/partnerships	
3	Partnership and sustainability: Connectors to their communities and builders of alliances and consensus	Two-way connecting policy makers and authorities to grassroots for commitment and sustainability and building and maintaining in a neutral way multistakeholder alliances	European Lung Health Group www.breathevision.eu https://www.efanet.org/about- efa/organisation/members https://www.efanet.org/about- efa/partnerships	Multistakeholders
4	Leadership: Developers and leaders of targeted action to their communities	Best placed to develop and take leadership on patient information, education, empowerment provided they receive the resources to do so	Finnish Asthma and Allergy programmes: specific actions led by organisations who are concerned by the action; patient organisations public awareness, patient information and evidence, education https://www.efanet.org/about-efa/organisation/members https://www.efanet.org/about-efa/partnerships	Multistakeholder
5	Communication: Implementers of information, tools, dissemination to their communities and capacity building	Direct reach, channels, narrative (science and policy => lay public), awareness and capacity building to, and knowledge of the target groups who are affected in a specific way	https://www.efanet.org/inform/expert-patient-network/3996-efa-capacity-building https://www.efanet.org/about-efa/organisation/members	https://www.efanet.org/about- efa/organisation/members

Closing section

7. You may wish to add other comments (e.g. on the structure of the approach, information gaps, recommendations for better supporting stakeholders).

Comments

(maximum 500 words)

It is particularly striking that the NCD initiative is lacking acknowledgement of allergy, despite its staggering prevalence and grave burden on patients, families and society at large. Allergy in all its forms (allergic rhinitis, food allergy, atopic dermatitis) is too often neglected in NCD discussions at the EU level, despite being among the most common diseases in Europe, the most common in children. Moreover, it is considered a risk factor for the development of other allergic and chronic respiratory conditions through a process known as the Atopic March. While we have highlighted some of these interactions in our submission on chronic respiratory diseases, much more should be done to legitimise the significance of allergic diseases that requires urgent and concerted attention.

The same is true for the health determinants of respiratory diseases. While the initiative invites input on health determinants, EFA identifies a knowledge gap invoked by the EC's rhetoric around lifestyle choices. Unfortunately, respiratory diseases are often thought of as self-inflicted or due to lifestyle choices (e.g., use of tobacco, diets etc.), which leads to stigmatisation and lack of political priority. However, we know that the causes of lung disease are much more nuanced than this. In this context, we urge evaluation and implementation of priorities and best practices with respect to the reality of lung diseases, and proportional to their burden as a leading cause of disability and death in Europe.

To facilitate this work, EFA highlights the <u>Breathe Vision for 2030</u> which aims to address gaps in European level policy attention to respiratory health, offering a unified voice on priorities and appropriate actions for awareness raising, improved prevention and care.

Regarding the form and implementation of these priorities and policy recommendations, we urge DG SANTE to work in concert with other relevant DGs to ensure cross-sectoral collaboration thereby ensuring an HiAP approach. Such an approach is an imperative given the multifaceted determinants of allergic and respiratory diseases, pertaining to many different policy areas and other diseases, including mental health and cardiovascular disease.

Finally, all stakeholders have a unique role to play in creating meaningful and relevant changes for both allergy and respiratory patients. Patient groups are fundamental in delivering patient education, developing new strategies for the management of chronic diseases and are willing and able to work hand-in-hand with healthcare professionals and policymakers. As representatives of patients living with chronic diseases, patient

groups are often lifelong partners, supporting and advocating for patients throughout their patient journey. Despite these efforts, <u>our research</u> highlights persistent gaps in many aspects of care, notably in self-management, leading to high rates of hospitalisations and emergency room visits, especially among severe asthma and COPD patients. Patient groups at national and EU level should be better supported to ensure patients are represented in decisions affecting them, including in the establishment of self-management plans with healthcare providers.

Please check the boxes that apply:

- ☐ I agree that a PDF of this document is uploaded to the Health Policy Platform NCD Stakeholder Group
- ☐ I confirm that the document does not include personal information (e.g. names and contact details)

Thank you for your contribution