# Open Call to Youth Organizations in the World Health Organization (WHO) European Region

## **Subject:** Online Consultation on the Voices of Future Generations

## Deadline for proposal submissions: 20 May 2021

## Theme: Youth Organizations, have your say! Shape tomorrow by speaking up today!

# **Section 1: Introduction**

#### How can you participate as Youth Parliament on Allergy and Asthma?

Youth organizations formally established as nongovernmental entities with non-profit, public-interest goals are invited to present their views. This could include, for example, grassroots community organizations, civil society groups and networks, faith-based organizations, and professional groups with members not older than 30 years of age.

Your organization is invited to:

- Consider the Commission's statement <u>'Rethinking policy priorities in the light of pandemics'</u>;
- Reflect on how the actions proposed in this statement address the needs of future generations;
- Consult with members of your youth organization to consolidate your feedback to this call;
- Enter your organization's inputs in the SurveyMonkey (link);
- If you have a story you wish to share, reach out to us at <u>eurofuturegenerations@who.int</u>

To participate, a youth organization or chapter should have active membership anywhere in the 53 Member States of the geographical <u>WHO European Region</u>. Kindly note that Individual or anonymous responses will not be considered.

If you have any questions about this Online Consultation, please forward them to EFA and we will reach out to WHO prior to the deadline.

#### Background of the Consultation:

The Pan-European Commission on Health and Sustainable Development is an independent commission convened by Dr Hans Henri P. Kluge, Regional Director of the WHO European Region, and chaired by Professor Mario Monti, to rethink policy priorities on health and sustainable development in light of the COVID-19 pandemic.

On 16 March 2021, the Pan-European Commission on Health and Sustainable Development released a <u>Call to Action</u>. It reflects on how health and sustainable development should be prioritized to set systems and societies on the right track for present and future generations to come, calling on national and supranational bodies for:

- 1. operationalizing the concept of One Health at all levels;
- 2. acting at all levels of societies to fix the fractures that left so many people vulnerable to the pandemic;
- 3. making changes to the global financial system;
- 4. promoting global public goods for sustainable improvements in health;
- 5. supporting innovation in health systems.

More details on the actions proposed can be found in this <u>link</u>. After reflecting on the list of actions proposed:

# **SECTION 2: Input from Youth Parliament on Allergy and Asthma**

Your ideas and voice matters. Tell us what you think can be done to help protect and benefit future generations under each of the actions proposed:

#### > <u>Question 1</u>: Operationalizing the concept of 'One Health' at all levels.

• **Context:** The 'One Health' approach is a holistic view of how humans, animals, and the environment all interact together. It is critical to addressing health threats, including infectious respiratory diseases, such as COVID-19. The areas of work in which a 'One Health' approach is particularly relevant include: food safety; the control of zoonotic diseases (those spread between animals and humans); laboratory services; neglected tropical diseases; environmental

*health; antimicrobial resistance. All these areas cover complex issues that require close collaboration across sectors, stakeholders and countries.* 

*Insert examples of interventions to better harmonize the sustainable interaction between humans, animals, and the environment.* 

#### Answer:

The European Youth Parliament on Allergy and Asthma is an initiative of the European Federation of Allergy and Airways Diseases Patients Associations (EFA) launched in 2020 to bring the voice of young patients and healthcare professionals across Europe closer to policymaking <u>https://www.efanet.org/inform/youth-parliament</u>.

The members of the Youth Parliament, we support the Pan-European Commission on Health and Sustainable Development's call to action. Our lived experiences underline the importance of focusing on the interdependence of human, animal, and environmental health. People with allergy and airways diseases act like radars of the healthiness of the environment, this is why prevalence, hospitalisations, deaths, and treatment use are very common indicators used to evaluate environmental effects on human health. Please find below our examples of interventions:

POINT 1.a: Climate change and air pollution, which affect biodiversity loss, animals, and humans alike, increases levels of CO2 and other pollutants in the air, which generates an increased pollen concentration and a prolonged or second flowering period and thus a prolonged pollen season. At the same time, air pollution indoor and outdoor air pollution can increase symptoms by making pollen more aggressive next to busy roads. We would truly welcome WHO initiative to set the basis for a systematic, real-time, monitoring system for pollen and air pollutants across the EU. Pollen monitoring is weak and not accessible for people living in Europe.

Drought and forest fires can additionally increase susceptibility to inflammation. This can lead to an aggravation of allergy and asthma symptoms. More frequent flooding due to climate change can also lead to mould growth and increased humidity, which is an ideal breeding ground for dust mites. To protect individuals from mould, it is crucial to focus on sustainable and allergy-friendly construction materials in new buildings.

POINT 1.b: We would like WHO to work closely with the World Meteorological Organization on this matter and to support the efforts of the European Aerobiology Society in gathering evidence of aeroallergens effects on health as well as liaise with EUMETNET and its AutoPollen project to develop better monitoring through national meteorological institutes. The still-forming immune system of young children is particularly sensitive to environmental factors, which is why a greater number of allergens in the environment also causes more and more allergies.

POINT 1.c: we especially support the establishment of an Intergovernmental Panel on Health Threats. The IPH can argue for the necessary reduction in air pollution and greenhouse gas emissions from the transportation, industrial, agricultural, and building sectors.

POINT 1.d: we cannot agree more with the proposal to develop a Pan-European System for Disease Control, as we witness today a fundamental gap in disease monitoring and prevention coverage in Europe: chronic diseases such as allergy and asthma are not followed as it should, and the existing European Observatory on Health Systems and Policies

mandate and other intergovernmental mechanisms seem too narrow to cover the leading cause of death in Europe as it should.

- Question 2: Acting at all levels of societies to fix the fractures that have left so many people vulnerable to the pandemic
  - Context: These actions include, for example, making health systems more accessible; addressing inequalities; better identifying vulnerabilities; and, communicating more effectively with populations.

*Insert examples of interventions to make societies more resilient, equitable, responsive, and inclusive to all.* 

#### Answer:

As European Allergy and Asthma Youth Parliament, we want to take a stance for health equity and accessibility of health systems and public places. Therefore, we especially appreciate the call to make health systems more inclusive by ensuring that everybody can participate in decision-making at all levels and can obtain access to health and social services.

POINT a - Chronic diseases such as allergy and asthma often come hand in hand, as co-morbidities, as co-burdens on the same patients. Allergies and asthma are commonly trivialised in our society due to a lack of effective communication on the severity of our conditions. The trivialization of allergy means that many costs associated with allergies are not covered by health insurances.

POINT b - The situation of children and young people access to the care they need is particularly vulnerable. Children and young people are typically dependent on whether their guardians take their illness seriously and are economically able to support them. Parents may be overburdened balancing this responsibility with their jobs and other caring responsibilities or, due to societal trivialisation, may underestimate their children's disease and accordingly fail to provide them with adequate care.

POINT c - The insufficient coverage of costs is also a significant inequality factor for children because, without financial support from a guardian, this can result in illness, reduced performance, social limitations, and deteriorating mental health. Therefore, the health status of children is thus directly dependent on the income of their guardian. In the 21<sup>st</sup> century, we need the urgent improvement of communication and health equity. Therefore, we would like to see Europe take steps to create equal access to medicines and eliminate of out-of-pocket costs to treat chronic diseases, especially if co-morbidities, as that leads people to choose the most important treatment neglecting others.

Efforts to stop the trivialisation of our diseases in society are necessary. For this, access to information and (digital) health literacy across all social stratification must be improved.

POINT d - As we look towards a post-COVID recovery, young people want to see environmental factors better considered in health infrastructures. To enable equitable participation in public life, a one health and health in all policies approach is necessary. For example, people with allergy and asthma encounter many obstacles in their everyday lives, most of which other people do not even notice. To create a barrier-free environment, public spaces must be designed to be allergy-friendly. For young people living with asthma and allergies, air pollution in cities must be reduced, and younger generations like ours are positive towards the expansion of active mobility, not only will it help create a more active society, but air pollution and greenhouse gas emissions will be combated, the health and well-being of the population will be promoted, and our allergy and asthma symptoms will improve!

People with house dust mite allergies suffer especially from upholstered furniture. Educational institutions and public transportation should rely on other materials for their seating so that all people can access these public goods without discomfort.

As services including cafes and restaurants reopen, food allergy sufferers may be prevented from participating in these social settings or can only do so with fear due to inadequate training of staff and allergen labelling requirements that are not taken seriously.

In order not to limit affected persons in their educational opportunities, career chances and social life, all of which can have an impact on a person's mental health as well as physical health, these barriers must be removed. We need more public investment in the social infrastructure. Otherwise, accessibility for people with allergies and asthma remains low. The consequences can be immense financial losses and reduced (mental) health for those affected.

#### > <u>Question 3</u>: Making changes to the global financial system.

• **Context:** The global financial system is the worldwide framework of legal agreements, institutions, and both formal and informal economic actors that together facilitate international flows of financial capital for purposes of investment and trade financing. How should the needs and aspirations of future generations be included in such systems? For example, current government debt will be left to future generations to pay off. In what ways should financial systems support future generations to achieve their aspirations, and not be a barrier for their future prosperity?

Insert what changes are needed in financial policy to ensure the prosperity of future generations.

#### Answer:

As the European Allergy and Asthma Youth Parliament, we demand that health equity must be at the forefront in all aspects influencing health, including the financial system. We call on public policy representatives to create and implement legal frameworks that do not create an imbalanced burden for future generations. Climate mitigation efforts and environmental protection are necessary for allergy and asthma sufferers and future generations to live a healthy life on this planet. Therefore, we appreciate that the Pan-European Commission on Health and Sustainable Development's call to action incorporates one health-related risks in risk analysis and risk mitigation systems. As mentioned in the call to action, health should be used as a criterion in the financial system. We argue to achieve this, Quality-Adjusted Life Years and Disability-Adjusted Life Years should be applied.

POINT a - Financial systems are linked to health equity because the socioeconomic status (SES) of an individual is directly linked to their health outcomes. People with a higher SES have significantly better chances to reach old age and have, on average, more healthy life years than people with a low SES. Currently, wealth is unfairly distributed in society, many low-income families cannot build up wealth across generations due to structural disadvantages. As SES is related to health outcomes, individuals from poorer backgrounds are therefore disadvantaged in their health outcomes. A more equitable society could be achieved through an earmarked wealth tax that benefits the whole population's health or is spent on disadvantaged groups.

POINT b - As emphasised in the Pan-European Commission on Health and Sustainable Development's call to action, major health crises can cause massive economic devastation. Therefore, we demand that we learn from the covidcrisis and stop the underfunding of health infrastructures and institutions. We do not want to depend on philanthropy but urge for prioritising the national health and education systems and their workers, which are the commonwealth of a country. WHO could lead the way by proposing a minimum percentage of GDP investment on health systems, to ensure our societies are ready to face the current health challenges and be fit for the next pandemic.

- > <u>Question 4:</u> Promoting global public goods for sustainable improvements in health
- **Context:** global public goods are public goods that benefit people worldwide, regardless of borders. Examples of global public goods include climate change mitigation efforts, infectious disease eradication, etc.

*Insert examples of global public goods for sustainable improvements in health, and how these should be promoted.* 

#### Answer:

As a youth patient initiative, we are proud to advocate for better health and prevention for our peers, but our role is not political. We will continue proposing new ideas, but we need an important collaboration. Most of them are proposed in question four and in our document present during the event "Growing up with Allergy and Asthma", but politicians must read and understand the importance they have for us. Our understanding from what public goods might be different than those ideas stated in the paper.

Prevention and care are two priority areas for the European Allergy and Asthma Youth Parliament, and we believe that they can be improved through digitalisation, as it happens now with interactive screens that visualise pollution levels or the availability of e-consultations. As young people, we think the investment in digitalisation for the common interest should be encouraged and protected, and therefore expect a solid regulation on the life cycle of health data for public health prevention and care purposes in the benefit of society.

Our Youth Parliament sees education around health and prevention as an important public good that should be available across Europe. Our goal is to increase awareness through public campaigns and events to create greater public understanding of the unique struggles young people face in their health, and how to help support us. We think WHO and governments should not only work at the political level, but also support civil society organisations like patient groups to disseminate their ambition, inform, communicate, and educate towards the changes that need to be done to achieve better health outcomes. As we have seen during the pandemic, every person counts, so everyone should be empowered to act for their own and our collective health.

One of the biggest problems for people with asthma and allergies is the limitations they are confronted to. Whether it is the fear of eating outside and being exposed to allergens, the flu symptoms due to pollen counts, or elevated air pollution that makes breathing difficult, all those problems also affect the overall population. Investing in mitigating risk-factors for chronic diseases will benefit every human in the planet.

- > Question 5: Supporting innovation in health systems
- **Context**: This includes the discovery and development of medicines, medical technologies, digital solutions, and organizational innovations within health systems, as well as enhancing transparency of public–private partnerships and their ability to deliver effective and equitable health care

Insert examples of innovations for health systems that would better attend to the needs of the youth and future generations.

#### Answer:

There are many gaps on how care is provided to young people in Europe that need to be looked at. There is the issue of transitioning between paediatric to adult care, which is a completely new universe for young adults, and not always happens with success. There are challenges on how young people with chronic diseases continue their healthcare at a period in life of intense mobility: young adults like us can travel a lot for educational or work purposes and might find difficulties in accessing care elsewhere, due to the fragmentation of healthcare systems and due to financial hardship.

We would also like to help developing new solutions for our disease areas, because we remain under deserved on treatment for many allergies and certain types of asthma. Young patients like us would like to participate in the definition of the research agenda, and in helping investigators develop better treatments: more personalised, with less adverse effects, and more accessible to those in need.

Finally, as the mobile-at-hand generation, we would like to see a faster introduction of digital health within the

healthcare systems, because we understand there are many solutions that are cheap, global, and largely accessible to the public. Scientists need to collaborate to improve our health and healthcare giving everyone the possibility to live the life they want at all. While we offer concrete proposals to improve the lives of young people living with allergy and asthma, we believe in collaboration. Our voice alone is not enough, so we need to be united to work towards a concrete goal.

#### > Question 6: Infodemics – the overabundance, false or misleading information

- Context:
  - 1. What have been the experiences of youth in seeking out health information (for example, regarding COVID-19)?
  - 2. Where do you seek out health information?
  - 3. What determines it as reliable, trustworthy, or useful?

Insert examples of ways youth consume health information, and how health information can be better framed, made available, and communicated towards youth.

#### Answer:

One of the reasons why people use the news, internet, and social media to take decisions about their health might be they have difficulties in accessing information from a healthcare professional. As patients, we really welcome the unveiling of healthcare professionals from all disciplines that have been pushed to the traditional media because of the pandemic. It is healthy to have their scientific opinion present in todays' discussions and we hope that it will be sustained post-pandemic.

People with allergies and asthma usually need to visit more healthcare providers (pulmonologist, allergist, immunologist, dermatologist etc.) than the average person, until they find the right and suitable therapy, where personalised therapy is key. Having access to **online counselling**, would be very helpful for young patients. Online counselling should include doctors with different specialisations, who can answer questions sent by patient via email. This would be important both now and post-pandemic, considering that the COVID-19 pandemic means it remains hard for patients to reach doctors, and to prevent similar issues in the future.

But we the young people, as many around the world, will continue trying to find a response to our questions in two clicks. Creating accessible and reliable medical information is highly important, especially for allergy and asthma that continue to be underdiagnosed despite increasing prevalence around the world.

We recommend WHO to encourage the following:

- clearly define the term reliable information. For us it should refer to information approved by public authorities, whether health ministries, EMA or WHO, or by third parties such as medical societies. Every Ministry of Health should list on its official website other **sites** that are useful and officially approved, so that patients can be sure that they are looking in the right place, and confident that the information is correct.
- Public health authorities should not only be active on traditional media but also monitor and use social media, as a tool to test public health education. We consider governments should be invested in counter resting fake news and the platforms that promote them with penalties. The public opinion should have access to reliable information in the places where the public opinion is being formed, and that includes social media high on the list. Many young people follow influencers and youtubers.
- Officially approved **apps** made for smartphones, about where to find the right information about healthcare, would be very easy for young people to access and use. These apps should be translated in as many different European languages as possible.
- Another method to collect and share information for young people is to organize an anonymous **questionnaire** for students (in student campus or online), about healthcare, or medicine in general. After collecting responses, to answer with the help of medical experts to publish in a student paper or online.
- Young people need access to healthcare information in different countries as they may travel, study, or work abroad. Therefore, the creation of an international medical healthcare **systems** would enable young people to have equal access to the healthcare they need. That would provide opportunities for students with asthma and allergies to study abroad without fear that they may run out of medicine or be prevented from accessing treatment or therapy. Student exchange programmes should be more affordable for young people with asthma and allergies, as health insurance can be expensive.

- As mentioned in our answer to Question 4, one of the most effective ways of raising awareness is through **education,** in elementary schools, high schools, colleges, workplaces etc. While this process would take a long time, it will lead to young people becoming more informed, find understanding, or even recognise allergy symptoms to support their peers.
- We also see the potential of **visual campaigns** such as organising photoshoots with people with allergies, asthma, and atopic eczema to exhibit those photographs in healthcare clinics across Europe. These posters should also inform people how to react if they witness someone having anaphylactic reaction etc.

#### **Question 7: Digital Technology and Health Systems.**

- **Context:** The pandemic has shown both the potential and shortfalls in the use of digital technologies in health and health systems:
- 1. What can we do to better exploit the potential of digital technologies, and how can we avoid some of the pitfalls (i.e., privacy issues, creating inequalities) and overcome these shortcomings?
- 2. What are some examples of technologies that have been used well in health care?
- 3. How should we embrace digital technology innovations in health care?

*Insert examples of how digital technology can support youth with their health and interaction with health care.* 

#### Answer:

Several ideas from Question 6 can be considered for this one. To elaborate on ideas: information on health from all official channels including websites, apps, social networks would be extremely valuable. If the channel is official, it would help young people to identify the information provided as reliable, checked with medical professionals, and would not provide misinformation.

The European Allergy and Asthma Youth Parliament believes that digital health records and electronic prescriptions would make travelling, school trips and student exchange much easier for young people to take part in, and not fear they are missing out on events with their friends, thus helping to prevent social exclusion.

We also see the importance of apps to measure pollen levels, other inhalational allergens, air pollution, and that these should be improved to help more young people use them to manage their symptoms. We also believe that access to online consultations, where patients can send their questions about healthcare directly to medical professionals and receive trustworthy feedback, will help healthcare become more accessible in the post-COVID future.

Are other concrete measures needed? For example, think about changes in the health and social care system, in how services are financed, digitalization of healthcare, research and innovation, consumption and production of goods, migration, gender equality, disability inclusion, etc.
Please insert your response (max 2500 characters)

We believe education should be a top priority. In education, we must involve not only children but also parents, to create a solid community that reduces stigma towards people living with allergies and asthma.

In operationalizing this call to action, how do you recommend governments and international organizations to engage with youth? For example, how can the participation and voices of youth be institutionalized in decision-making bodies, advisory groups, or similar engagement mechanisms, or in the adoption of specific laws and regulations, etc.
Please insert your response (max 2500 characters)

There should be an integration of youth voices across policies, and not just those that are earmarked as addressed to the youth. Healthcare and social are policies affecting youth and therefore their input should be sought. Young people bring different insights to the table, and institutions should offer more mentorships opportunities for young people to gain the necessary skills from senior health advocates and professionals. It is furthermore crucial to include young people also in work settings. Hiring a sufficient number of young professionals and training them while incorporating their accommodation needs, not just as a token to check off "youth participation", would empower young people most. We also believe trainings and guides should be offered on how to talk with policymakers (online or in person), so young people can directly express their needs to policymakers.

• To elaborate on your response to the previous question, please share examples of how youth have been meaningfully engaged in past decisions that affected their health and well-being, from agenda-setting, decision-making, and implementation of actions:

Please insert your response (max 5000 characters)

Add document, weblinks or similar to support the example(s) shared.

Included EU Policy recommendations from EA2 Youth Parliament

#### Allergy & Asthma - Political Initiatives (allergyasthmaparliament.eu)

Youth Parliament member Laura Stenz represented the German Allergy and Asthma Association DAAB in the Children's Commission of the German Federal Parliament. Link in German:

https://www.bundestag.de/kiko#url=L2Rva3VtZW50ZS90ZXh0YXJjaGl2LzIwMjEva3cxMi1wYS1raWtvLW5hY2hoYWx0aWdrZWl0LTg yOTE2Mg==&mod=mod539494