European Youth Event

Report

European Allergy and Asthma Youth Parliament

2023

#AllergyAsthmaYouth

Photo 1: The EFA/Youth Parliament delegation included eleven young allergy and asthma patients advocates from seven countries: France, Greece, Ireland, Italy, Poland, Spain, and the United Kingdom.

On 9 and 10 June 2023, the European Allergy and Asthma Youth Parliament participated in the landmark European Youth Event (EYE), celebrated in Strasbourg, France.

EYE is a biannual youth event under the umbrella of the European Parliament, bringing together young people from across Europe to meet, network, share experiences and get closer to the EU, its policymakers and institutions.

In this fifth edition of the event (#EYE2023), the Parliament welcomed more than 8.500 young people in person - and even more online.

Participants could choose among more than 300 activities concerning a wide variety of topics, including the environment, climate, health, culture, migration, digital policy, issues related to social and human rights – and, of course, the EU elections in 2024!

Most activities in the two-day programme were organised by youth groups and networks from across the globe. However, there were also sessions hosted by EU institutions such as the European Parliament, the European Commission, the Council of the EU, the European Ombudsman; or even international bodies, such as the Council of Europe, the Organisation for Economic Cooperation and Development, and various UN agencies.

As expected, the importance of the event attracted a large number of distinguished speakers. For example, about 31 MEPs were in place joining the EYE sessions, including three EP Vice-Presidents and the EP President Roberta Metsola. Representatives from various EU and international bodies, as well as national politicians also shared their interesting insights.

Given the status of EYE as one of the biggest and most important youth events in Europe, the participation of European Allergy and Asthma Youth Parliament provided a unique opportunity to showcase issues that concern young allergy and asthma patients. Selected among more than 200 other proposals, the event of the European Allergy and Asthma Youth.

Parliament with the title 'Let's Rebuild the Healthcare Systems' looked into the challenges and promises of digitalisation for European healthcare systems. Organised over two days, the sessions aimed to steer reflection on effective policies on digital health; and address the role of citizens, particularly the youth, within the digital transition in healthcare. The ultimate goal was to foster an exchange on how digital health can effectively deliver to the needs of young patients and the society, especially in post-COVID times

Both sessions were run with full capacity (40 participants each day), as the event triggered interest from young people attending EYE activities, who brought a variety of different perspectives to the discussion table.

A key part of the sessions was a game-based workshop centred around two giant Jenga towers that represented the healthcare systems. Participants were asked to place their digital health ideas in the Jenga bricks, without making the tower/healthcare system collapse. In this cooperative way, participants shared ideas and engaged in lively discussions, while having the big picture of the many building blocks in a healthcare system (i.e. policies, infrastructure, stakeholders, care programmes).

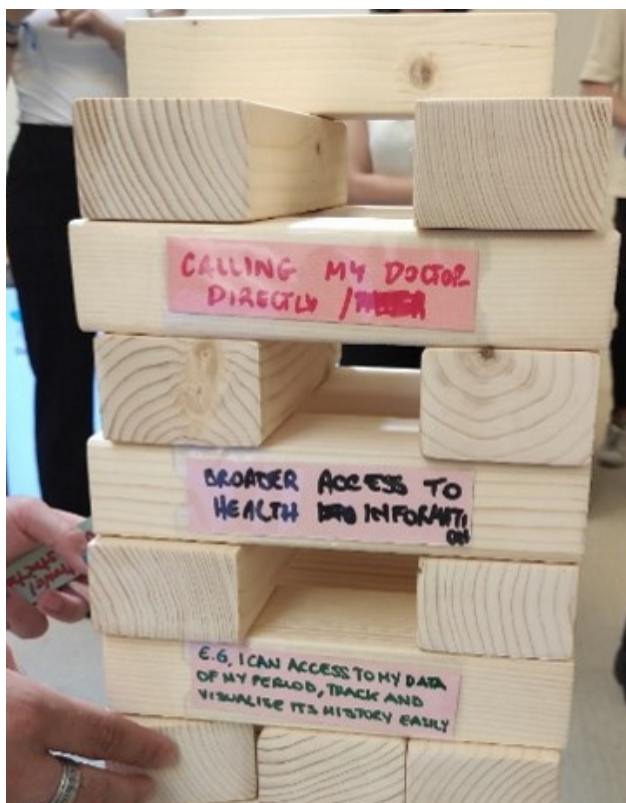If the tower happened to collapse, everyone had to help build it back!

Photo 2: A Jenga healthcare system, labelled by participants during the EYE 2023 sessions.

Day 1: The added value of digital health

Day 1 began with a presentation of the activities of the European Allergy and Asthma Youth Parliament and the introduction to the main aspects of digital health. Digitalisation is one of the transitions of our time and it will bring ground breaking changes to health and care. Digital health has the potential to empower people, improve their health through better disease management, enhance the delivery of

care, promote access and equality for all and push research and innovation to unknown limits.

As any big transformation, digital health is raising deep considerations too: How are our **health data and privacy** protected? How can we ensure in practice **equal access to digital health solutions** for all? How do we address **digital literacy gaps?** How can we be certain that digital solutions **respond to the needs of real patients in real life?** And more specifically, will it serve to ensure **young people needs' are addressed** in digital health and care?

As all EU Member States healthcare systems differ from one another and there are many digitalisation disparities, the EU is working on cross-border frameworks to harmonise healthcare markets, enable health research and mobility at Union level. Upcoming legislation, such as the European Health Data Space and the Artificial Intelligence Act, are expected to play a major role in the structure of digital health at the national level.

With that background, participants were asked to respond to questions in two different towers.

Tower 1: Which digital health aspect is the most helpful or the most popular among the youth?

Tower 2: How does digital health technology benefit patient's health and day-to-day life?

Photo 3: Young EYE 2023 participants working in teams to digitalise the mock-Jenga healthcare systems that will fit patients' needs.

The possibility to conduct **online clinical trials** emerged as as one of the key topics in the discussion. Digital health technologies are being used in clinical trials at step 2 and 3, and they serve to enlarge the research with a wider range of participants.

participants also referred to the usefulness of **digital health tools that support disease monitoring**, such as devices to track glucose levels and e-Health technologies that help people better monitor their digestive conditions. A young asthma patient shared his good experience with a **mobile application** that helps him track his peak flow, allowing him to adjust his activities more accurately.

Another popular topic among the young attendees was **the use of artificial intelligence, or AI**, for disease diagnosis, an innovation that comes with benefits and risks. Overall, participants stressed that AI diagnoses have proved more accurate than those of doctors in some cases, and that AI results should be consulted by doctors in their practice. On the other hand, AI could bring the risk of overreliance on a model or tool, and and the possibility of false negative results could have on patients.

Participants also exchanged around the benefits of using social media as a vehicle for health literacy and advocacy, but also the possible risks of its misuse, such as the impact on mental health.

The discussion also covered **technologies that provide tailored information about certain risk factors**, such as air pollution. EFA highlighted that the increase of air pollution, including pollen emissions, is correlated with the rise of allergy and asthma Europe. Therefore, informing patients on the levels of air pollution through digital means is an effective way to improve prevention of airways disease and symptoms.

Overall, it was agreed that the normalization of digital health in Europe has been a key result of the COVID pandemic, as it **helped European healthcare systems and patients cope with the emergency** and triggered a revolution at the national level.

Photo 4: EYE 2023 participants against the task of re-building a just-collapsed Jenga tower.

Day 2: Challenges and opportunities for digital health

The session of Day 2 was opened by **Member of the European Parliament Sirpa Pietikäinen** (European People's Party – Finland), who brought her perspective on the work of the European Parliament on health policies.

In her speech, MEP Pietikäinen praised the role of groups like the Youth Parliament in amplifying the voices of young people in European politics. Politicians should always keep open ears for the youth, as they have been elected to represent all European citizens.

The MEP referred to the big debate around the EU competences on public health, stressing that Members States do not have the skills to tackle all the health needs alone, as it has been shown with the pandemic. Therefore, EU initiatives such as the European Health Data Space will be key **in addressing cross-cutting challenges such as access to care, responding to patients' needs**. The privatisation of information, and the issue of health data privacy, are major aspects of the future of digital health data in Europe.

In this context, Ms Pietikäinen emphasized the important role of the European Parliament in shaping EU policies on digital health and particularly in protecting the rights of people in the EU.

MEP Pietikäinen encouraged the audience to actively engage in European politics and the wider political life through all possible channels. She conveyed that a strong collaboration between policymakers and citizens is a prerequisite for informed and effective policymaking and she closed her remarks with an empowering for the young attendees: "the power lies in the group, individuals, and their knowledge".

Photo 5: MEP Sirpa Pietikäinen addressing young allergy and asthma activists during EYE 2023.

The speech was followed by Q&A where participants could address questions to the MEP.

The topics of the second session were:
Tower 1: What concern you the most when using digital health technologies?

Tower 2: What measures and policies should be put in place to overcome the challenges and barriers?

Photo 6: Participants during the session

Like the previous day, the Jenga towers were filled up rapidly with input from participants. Several issues emerged at central stage in the fast-paced conversation that followed. For example, participants highlighted the importance of the **social bond between patients and healthcare professionals**, expressing fears around the impact

digital means and telemedicine could have in the patient-doctor relationship. The views expressed showed that while tools like online consultations are useful when accessing and delivering healthcare, the human contact between patient and healthcare professionals is highly valued by young people and should not be scrapped out.

Attendees also raised concerns around cybersecurity, health data leakages and data ownership, which are crucial issues in a digitalised healthcare system, given the high sensitivity of health data. To this end, future EU frameworks on health data should ensure a strong safety net for patients, through tools that require informed consent and provide immediate access to, and full ownership of, their health data.

Another topic firmly brought to the table were the worries about **existing, and maybe increasing inequalities** among and within Member States regarding advances in digital health. It was noted that in some areas, healthcare systems are digitalising at a different pace than patients and doctors do, leaving them effectively behind, or even completely out of the process.

The discussion continued on the persistent gaps in **digital literacy**, which can be very prominent both among healthcare professionals - especially when overworked- and vulnerable groups, such as the elderly. EU-level actions must aim to reduce these gaps through continuous education and training for the most in need of health literacy.

Overall, participants agreed that digital health technology is key to **a more personalised and patient-centred approach to medicine**, but that it should still aim to become more efficient and burdenless in the delivery of care to the patient.

Photo 6: Members of the European Allergy and Asthma Youth Parliament, EFA staff and MEP Sirpa Pietikäinen at EYE 2023.

Evaluation

At the end of the sessions on both days, the EFA staff distributed evaluation forms to all participants. According to the analysis of the results, the sessions were rated 4.29 out of 5 by the participants, who have found the workshop useful (4.36 out of 5) and almost all of them declared they learnt from it (96%).

The event of the European Allergy and Asthma Youth Parliament in EYE2023 resulted in two more young patients joining the group, expanding the geographical coverage to Greece and Belgium.

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The European Allergy and Asthma Youth Parliament brings together young allergy and asthma patients and medical professionals between 16-30 years from across Europe. The Youth Parliament is a forum to share experiences and knowledge, to raise awareness for the pressing issues for young patients, and to inform European policymakers on how their work can support young people living with asthma and allergies.

To find out more about the Youth Parliament, contact:
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