MEP Lung Health Group Event report:

Improving lung health through the future European Health Data Space

A BREATHE Vision for 2030.

European Parliament Lung Health Group
February 8 2022, 14h00-15h15 CET
Hosted by MEPs Manuel Pizarro (S&D – Portugal) and Sara
Cerdas (S&D – Portugal)

On 8th February the MEP Lung Health group, steered by the European Lung Health Group (ELHG), launched its Policy Brief on the Future of the European Health Data space during its event, 'Improving lung health through the future European Health Data Space'. The virtual event was co-hosted by MEPs Sara Cerdas (S&D – Portugal) and Manuel Pizarro (S&D – Portugal) and brought together 236 participants of the 533 registered.

The ELHG brings together patient groups and societies of health care professionals that aim to increase awareness and prevention for respiratory health by 2030, improving lung health care and research. The BREATHE Vision for 2030 seeks to influence European and EU policy priorities to maximise their benefits for respiratory health. Through the MEP Lung Health Group, the ELHG engage with European level stakeholders to encourage them to recognise respiratory health as a public health priority and to take action to improve the quality of life of lung disease patients.

The event marked the launch of the ELHG Policy Brief on "Improving lung health through the future European Health Data Space" with the aim of highlighting the opportunities it brings for patients with lung disease and healthcare providers, with concrete demands to make these benefits a reality. The Policy Brief calls for a European Health Data Space (EHDS) that responds to the following patients and healthcare professionals' expectations:

- A European Health Data Space to facilitate virtual and in-person care for respiratory disease
- A European Health Data Space to increase access to quality care and information
- A European Health Data Space that functions with transparency and fosters participation
- Health data space to enable effective research on respiratory disease
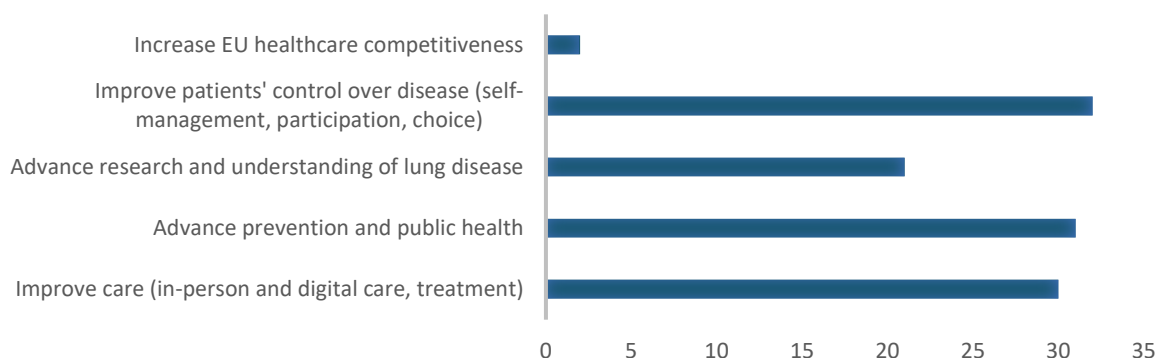
Opening remarks

In anticipation of the European Commission's EHDS proposal, the launch featured digital health actors who came together to discuss how the expectations from the respiratory community could be reflected in the future EHDS legislation, and whether EHDS has the potential to improve prevention, diagnosis, management and quality of life for people living with lung diseases. The event was moderated by Dave Keating, journalist at France 24.

MEP Sara Cerdas (S&D – Portugal) opened the event with a statement that the EHDS, a topic the European Parliament has been very vocal about, provides opportunity for better healthcare development through the integration of technologies to improve patient information, prevention, care and research. She provided an overview of the various opportunities and concerns that legislation had to assess to create a strong and safe legislative framework for a robust EHDS.

Before the panel discussion began, participants had the opportunity to respond to a poll to better understand what they considered to be the most important objective for the EHDS to benefit lung health. The results showed a large plurality suggesting that improving patient's control over disease, advance in prevention and public health as well as improving care, are all very important to those present at the event

What do you consider the most important objective for the European health data space to benefit lung health?
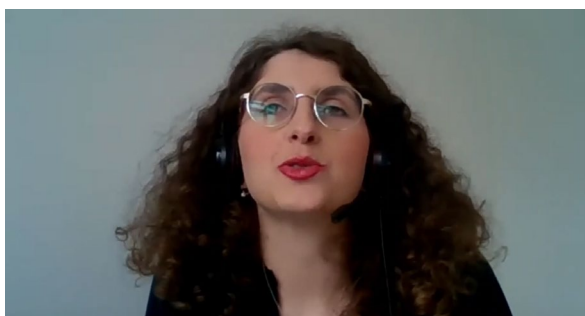

Panel Discussion

Dave Keating, kick-started the discussion with panellists on how the expectations from the respiratory community could be reflected in the future EHDS legislation, given its huge potential to improve prevention, diagnosis, management and quality of life of people living with lung diseases.

EHDS – dream or reality?

The first question asked to all panellists was: As the European Commission proposal is being awaited - is its ability to contribute to improving lung health prevention and care a dream or reality?

Ornella Martinello - European Commission Secretariat General

Prof. Arzu Yorgancıoğlu, Advocacy Chair of the European Respiratory Society (ERS), offered the perspective of the lung health community. She expressed the hope of patients to benefit from the higher digitalisation of healthcare services.

Prof. Yorgancıoğlu reflected that, just as the poll suggested, it is crucial for the lung health community to increase their control over their health and their data. She concluded that it is in the hands of all stakeholders to make this dream a reality.

Prof. Arzu Yorgancıoğlu – ERS

Mr. Armando Ruiz, Board Member of the European Federation of Allergy and Airways Diseases Patients' Associations (EFA), echoed the importance that the EHDS represents for the lung health community and patients. He highlighted three areas that require strong focus for this reality to be viable: (1) patient involvement in the development of digital solutions, (2) strong exchanges and connectivity across healthcare systems and (3) trust and transparency in data sharing.

Armando Ruiz – EFA

Ms. Sarah Collen, Co-Chair of the BiomedAlliance Taskforce on Health Data, shared her experience with issues relating to Real-World Evidence and Big Data, which are central to the EHDS' functioning. She emphasised that there are lessons to be learned from projects around the challenges faced. A recurring challenge is accessing data that is either not fit for purpose or of sufficient quality to be used for research purposes and this is a challenge that the EHDS aims to address to have real value for research.

Sarah Collen - TEHDAS

Marc Lange – EHTEL

Finally, **Mr. Brice Van Eeckhout** of Comunicare Solutions SA and participant in DRAGON (IMI Project) put forward the importance for patients to have control over their diseases, a core element of his project, which starts by developing tools with patients. He highlighted barriers still faced in this process due two scattered and vague legislation that needs to be addressed through the EHDS, for data to be shared and processed safely and transparently. Once these barriers are addressed the EHDS can offer the promise of strong healthcare innovation and improved quality of life for patients.

3

Brice Van Eeckhout – Comunicare Solutions SA

Digital health technology to serve respiratory disease outcomes – a change in paradigm?

Digital technology offers many new ways to manage our health systems. These come with new behaviours, adapting habits, learning new ways of doing – and for some COVID-19 has accelerated this change. **Prof. Yorgancıoğlu** believes this momentum can be extended beyond the pandemic to non-communicable diseases. She urges the European Commission to press for greater data sharing by patients across the EU and to ensure that by 2030 data can be accessed safely by researchers to improve medical research. This acceleration represents a clear paradigm shift for **Mr. Ruiz**, who describes new digital solutions that support clinical practice as lifesaving, as they can reduce the high number of misdiagnoses.

Mr. Lange adds that, on top of the creation of new care models, there is also an increase in availability of data and, as a result, an increase in analysis to improve prevention. This however does not come without its challenges which will require a legislative and budgetary move from data analysis for care to prevention budgets.

Digitalisation to enable self-management – what role for patients?

When asked about the role of patients in this change of paradigm, **Ms. Martinello** said patients are central to the way we provide healthcare, and we need to create an EHDS that ensures they have appropriate and future proof care and disease management. As the European Commission prepares its proposal for the EHDS, they are aware of the central role that patients should play and there is a mission to empower patients, improve their digital literacy and strengthen their rights for the EU. In order to give patients the space they require in digital health, first it must be ensured they trust that their data is safe. Ms. Martinello also explained that giving patient communities a central role is an important way to foster progress and innovation.

Mr. Van Eeckhout described the need to address patient literacy, which begins with understanding what data is presented to the patient and having tools to address which data needs to go to patients and which ones to healthcare providers.

Beyond patients as users and involvement in development, **Ms. Collen** expressed that patients should have a say also within the governance level. She believes that patient representatives can be crucial in the discussions which tackle sometimes quite deep, ethical, legal challenges.

Speaking for patients, **Mr. Ruiz** stated that self-management is where most of the patients role will be. He sees strong opportunities for patients and healthcare providers to work together for better health management that within this new paradigm can help us to develop these new technologies and use the data to engage with patients and build on their responsibilities.

Questions from the audience

The ensuing Q&A session created discussions on ways to bring forward the best scenario for a successful EHDS.

Partnerships with broad stakeholder involvement are for the speakers an important element, from both the industry perspective for

Mr. Lange but also from a lung community perspective to which **Prof. Yorgancıoğlu** added that both patients and healthcare providers are eager to be part of these partnerships. Partnerships with stakeholders are at the core of the projects in which **Mr. Van Eeckhout** is a part of. He attested that it is crucial to creating strong tools but also to help patients and healthcare providers adapt to the paradigm shift that we are experiencing.

This adaptation requires acknowledging digital health literacy as suggested by one of the participant questions. For the European Commission, **Ms. Martinello** stated both digital literacy and health literacy are elements that need to be addressed if the EHDS is to be successful. In **Mr. Van Eeckhout's** experience, digital health literacy challenges can be addressed by making tools user friendly, and working to improve awareness and health literacy can prove useful. In a more hybridised health system, **Mr. Lange** reminds that before digital literacy, it is important not to forget digital access which is not yet universal.

Mr. Ruiz summarised this discussion on digital health literacy by explaining that it is a considerable challenge that sits at the core of the EHDS. It is essential that digital access is ensured for equity, with parallel ways to address both health literacy and digital literacy. Leaving anyone behind should not be accepted. **Prof. Yorgancıoğlu** expressed that achieving this is possible by investing in digital literacy which **Ms. Martinello** echoed, stating that in the shorter term working with tools that can be both online and offline such as the EU COVID certificate can provide such a transition. Speaking from patient experience **Mr. Ruiz** then adds that beyond patient access, healthcare access is essential so that systems are connected across Europe.

Looking at tools and innovation, **Ms. Collen** answered a question on Artificial Intelligence (AI) to explain that inequality and bias are also driven by the data. The EHDS will bring in a large amount of data and the higher the quality of the data, the higher the need to make sure its interoperable. Once data is managed correctly it can help to guide research and decision making. Ms. Collen

stated there is room for exciting innovations that will occur over the coming years because of AI.

With this influx of data, **Mr. Van Eeckhout** answered whether the data is coming from patients or healthcare providers. For projects he is implicated in, patients are the ones targeted to input their data. However, different tools can be made for different users at it is there that the EHDS can bring clarifications at a legislative level on who has which responsibilities.
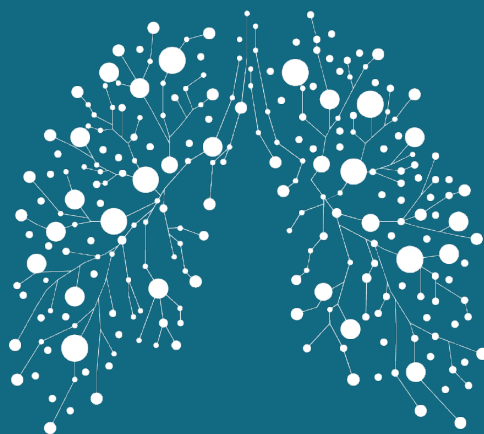
The panel discussion concluded on the importance of a patient centred EHDS that combines patient and clinical data for improved prevention, care and innovation.

Concluding remarks

At the close of the event, **MEP Manuel Pizarro** echoed the panellists who throughout the discussion showcased the opportunities brought about by the EHDS. The first conclusion he took from the conversation is the eagerness of lung health patients and healthcare providers have for an operational EHDS. It cannot be effective without their involvement and their involvement is twofold: (1) active digital data collectors and providers and (2) primary beneficiaries of health data systems. These roles then help consolidate a powerful EHDS that can facilitate care, improve transparency and improving participation and research. The EHDS will require innovation from Member States and EU programmes such as EH4Health, Digital Europe as well as strong legislation at an EU level through regulator bodies. Strong standards and legislation will allow for progress for citizens and patients.

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Watch the event recording

European Lung Health Group:
https://www.efanet.org/inform/lung-health-group

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