

EUROPEAN HEALTH PARLIAMENT

EUROPE'S NEXT GENERATION OF HEALTH

EUROPEAN HEALTH PARLIAMENT

RECOMMENDATIONS BY
THE NEXT GENERATION

#WeRun4Health

2018-2019



TABLE OF CONTENTS

FOREWORDS

› Zeger Vercoouteren	6
› Nicola Bedlington	7
› Olivier Costa	8
› Thomas Gelin	9
› Shéhérazade Semsar-de Boisséson	9
› Adam Mouchtar	10
› Katarína Gatialová	11
› Antonio Tajani	12

RECOMMENDATIONS

› MAKING EUROPE HEALTH LITERATE BY 2025	14
→ Committee on Health Literacy and Self-Care	
› PATHWAYS FOR A HEALTHY STATE OF MIND IN EUROPE	24
→ Committee on Disease Prevention and Management	
› CONNECT - SHARE - PROTECT	34
→ Committee on Data for Healthy Societies	
› LETTING EUROPE BREATHE	44
→ Committee on Human Health & the Environment	
› LEADING HEALTH INNOVATION TOWARDS VALUE IN EUROPE	54
→ Committee on Innovation & Value	

EUROPEAN HEALTH PARLIAMENT (EHP)

The European Health Parliament (EHP) is a Brussels based movement connecting and empowering the next generation of European health leaders to rethink EU health policies. Along with its partners: Johnson & Johnson, POLITICO, European Patients' Forum, EU40, College of Europe, Porter Novelli, the EHP provides the next generation of European leaders with the connections, knowledge and platform they need to build a healthier and more innovative Europe.

The EHP answers Europe's need for fresh ideas in health. Health systems are facing immense pressures to adapt their spending and other resources to match changing demographics, rising disease burdens, stronger patient empowerment and modern technologies. The EHP believes that the solutions required must come from the young European health leaders who influence the policies that will ultimately concern their generation as they age.

That is why the EHP was created in 2014. The initiative connects promising young professionals and challenges them to develop solutions for European health policy that are both innovative and actionable.

Each year the EHP convenes a diverse group of 60 young professionals representing all healthcare sectors. Participants work together for six months to develop policy recommendations that address today's most pressing European health issues, which are picked in cooperation with the European Commission. EHP participants are selected for their contribution to and potential to lead in European health policy and come from a range of educational and occupational backgrounds. Their recommendations are published around Spring.

**This year, #WeRun4Health
ahead of the 2019 EP
elections.**





FOREWORDS

Zeger Vercooteren

Vice President Government Affairs & Policy
EMEA, Johnson & Johnson

4th Edition of the European Health Parliament (EHP) – Approaching 2019 Elections, EHP Members Will Run for Health!

Fourth annual health initiative meets from September 2018 through to April 2019

The EHP helps students and young professionals from very diverse backgrounds and nationalities to connect very genuinely with the European project. EHP provides these next generations of European leaders with the connections, knowledge and platform they need to build themselves a healthier and more innovative Europe.

Health systems are facing pressures to adapt their spending and other resources to match ever-changing demographics, rising disease burdens, stronger patient empowerment and modern technologies. This calls for greater innovation and collaboration from all areas of academia, industry and policy. The EHP answers Europe's need for fresh ideas in health. Indeed, resulting from this initiative are a series of recommendations for European health policy that the young authors present to policymakers ahead of the 2019 European elections.

What sets this unique initiative apart is the fact that the EHP members voice the concerns and aspirations informed citizens have for European health policy. Their recommendations are actionable and to the point. This makes – and has made – their work so valuable to the institutions and policymakers as demonstrated by the great interest and engagement of, among others, the European Health Commissioner, Vytenis



Andriukaitis or the President of the European Parliament, Antonio Tajani, who shared his views on EHP's important contribution to EU health policy, bringing disruptive ideas to shape a healthier and more innovative Europe. Johnson & Johnson, in collaboration with the other EHP partners, truly pride itself on preparing and empowering EU young professionals to advocate for what matters most to their generation.

The 4th European Health Parliament is a special edition: it meets as Europe prepares itself to vote for a new European Parliament next May. EHP members will campaign too, running for health to be a priority in the next Commission and Parliament. Our members and the alumni network (+ 180 professionals) will make their voice heard throughout the election cycle, both physically at the planned Spitzenkandidaten debate and throughout Brussels, and online through video interviews, a video challenge and social media.

Follow the buzz generated on social media by this young but knowledgeable crowd – let's all join this year:
#WeRun4Health!

Nicola Bedlington

Secretary General,
European Patients' Forum

It has been a pleasure and an honour to have been part of the 2018-2019 edition of the European Health Parliament. Once again, the contribution of so many talented young professionals who have worked hard in identifying and tackling the most pressing challenges for health in Europe was impressive and extremely timely for the much-needed reshaping of EU health policy.

The Parliamentarians have brought many issues to the fore, all of which were highly pertinent to current challenges the health sector is facing at EU and at national level. The increasing health inequalities and lack of access throughout Europe require fresh, innovative solutions.

With the European Elections, this year has been a crucial stepping stone towards the future of health in Europe. It was particularly stimulating to engage in conversations with candidates running for the new European Parliament, on the five specific topics addressed by the committees.

With an estimated 150 million (and increasing) Europeans living with chronic conditions, we need to continue awareness-raising and strive to make health-related issues a priority for the EU agenda. These past six months it was great to see this strong team of motivated and knowledgeable individuals address these issues with expertise and competence and develop concrete and evidence-based recommendations.

I was also happy to note that this year's EHP reflected a strong patient perspective, which added even more legitimacy to the EHP, and a level of authenticity to the discussions. We may have the expertise and knowledge from working in the health sector, yet nobody will help us drive positive change than patients themselves. They have invaluable experiential knowledge and expertise through living with a disease and navigating the health system.



Political figures such as European Parliament President Tajani and EU Health Commissioner Andriukaitis have picked up on these efforts – this is excellent news, and it adds even more credibility to the initiative. But the hard work will only be paid off when concrete action is taken, commitments are met, and recommendations are implemented.

The new European Parliament and Commission will shape the future of health at EU level, but collective energy of the EHP are a driving force.

My warmest congratulations to everyone at the European Health Parliament – onwards and upwards!

Olivier Costa

Director of European Political and Governance Studies, College of Europe (Bruges)

The importance of public health for European societies is currently undervalued because of the focus of policy-makers, the media and citizens on other topics, such as the refugees crisis, the state of international relations, or climate change. It is nevertheless a central concern for all of us.

As life expectancy starts, for the first time in decades, to decline and as social protection systems are defied in most of the member states, improving or maintaining public health at a reasonable cost is a major challenge. Ambitious reforms are required, especially at EU level, but there is no consensus on the objectives and the means. In the current context, EU actors are not able to provide an efficient brainstorming and tend to favour self-restraint.

There is consequently a need for initiatives from the civil society to nourish the European debate on health. Since 2014, the European Health Parliament has proven its capacity to contribute to this process. Gathering a group of young professionals and post-graduate students to confront their views, experiences, data and ideas is a way to bring inspiration to EU policy makers. The EHP project works out because participants are convinced that it is the responsibility of citizens, media, private companies, higher education institutions and civil society organisations to contribute to the EU policy-making.



The College of Europe, which has been preparing young Europeans for leadership functions since 1949, is most grateful to its partners (Johnson&Johnson, Politico, EPF, EU40, and Porter Novelli) for this unique opportunity. For us, initiatives like the EHP are crucial: our mission is not only to teach students in an academic way, but to give them a concrete experience of the EU policy making and to encourage them to develop their critical thinking, their capacities to work collectively, and their concrete involvement in EU affairs.

We are very proud of the 10 College students, who worked passionately within the EHP, on top of their very demanding study programme. I hope that the analyses and proposals of the Fourth EHP will inspire once again EU policy makers, especially in view of the new legislature.

Thomas Gelin

Senior Vice President, Healthcare,
Porter Novelli



The European Health Parliament (EHP) was established in 2014 with the objective to connect and empower the next generation of health leaders to provide disruptive, actionable solutions for health in Europe.

And EHP has truly lived up to its ambition. Each year, members interact with top policymakers, media, and the influential players driving public health policies to help position health issues on top of the European agenda. This movement has gained incredible support among key decision-makers and stakeholders seeking for innovative, multidisciplinary solutions in health.

I am very pleased to be supporting such a vibrant, collaborative and forward-thinking community of passionate young leaders. Their policy recommendations will undoubtedly help address Europe's most pressing health issues and inform important policy discussions ahead of the European Elections.

In 2019, **#WeRun4Health!**

Shéhérazade Semsar-de Boissésou

Chief Executive Officer, POLITICO Europe



POLITICO has been a partner of the European Health Parliament (EHP) since its very first edition in 2015, when POLITICO and the EHP were both new to Brussels.

Since then, we've watched the Parliament grow, evolve, and challenge the health care dynamic in Brussels and abroad. In each edition we've been impressed with how the new Parliament has built on the work of the previous years, created their own thoughtful recommendations, and observed, absorbed, and contributed to the current policy conversation. This fourth edition of the EHP is no exception.

As a non-partisan publication, POLITICO does not advocate for any policy or political position. We do recognize disruptive ideas and those who dare to think differently. With that, we're excited to see the recommendations put forth by the 2018-19 EHP.

Adam Mouchtar

Managing Director,
EU40

It is an ancient Achilles heel of representative democracy to have representatives take decisions in areas they are not fully accustomed with. By definition, they cannot understand the intricacies and complexities of each and every policy subject they are legislating on. By listening to experts, and only then making informed decisions, we can create good policies that truly represent a compromise between all affected interest groups.

The beauty of the EHP is that people working in the health field are at present from the starting point. Their presence and knowledge, allows politicians to fetch from the most authentic source possible: young health professionals.

Professionals who have experienced and been confronted with the shortcomings of the current health sector, who however still having a fresh eye and a strong motivation to drive the necessary changes in the sector.

The Achilles heel of solely allowing experts to formulate policies is that they often do not respect the aspect of viability. They formulate ideals that nobody can realise, thereby building castles in the sky. Hence, a balance between experts and policymakers is needed.

The beauty of the EHP is that young health professionals are matched with policymakers, public affairs experts and academia from the get-go. They formulate their ideas and visions under constant guidance of those, who understand the complex mechanism of a parliamentary democracy. They possess the experience of what usually finds majorities and support and what does not. As EU40 we are proud of the role we have been able to play here, as a hinge between the young participants of the EHP and our young politicians.



Last year we experienced how health EU Commissioner, Vytenis Andriukaitis, used the fully filled well of ideas the EHP has created over the years, and announced his priority to create IT platforms to store all patients' health records in the cloud, making them accessible across Europe. Quick accessibility to health records for a doctor in an emergency situation is pivotal, avoids unnecessary errors, and could save many lives. The fact that this idea was developed by the EHP made him more believable as a politician. He is now supporting the ideas of those, who know and understand what changes are needed. Instead of being a politician operating out of an ivory tower, he is now the defender and promoter of those, whose complaints and ideas usually go unheard. The EHP created a win-win situation for the health sector and politicians, and EU40 is proud to be a part of that. As a network and platform for young Members of the European Parliament (MEP), we are thankful to be able to expose our MEPs to the opportunity to support so many good ideas that have the genuine potential to make Europe the world's healthiest continent.

Katarína Gatialová

EHP President 2018/2019



The Year of 2019 is undoubtedly a breakthrough for Europe. With Brexit, upcoming European elections and formation of the new European Parliament and Commission, we are present at the time when the course of Europe is changing. From the impact of digitalization on society, to doubts about globalisation, security concerns and the rise of populism, it spells out the challenges we face: will health still remain on the list of priorities for the European Union? Will health be swept along by many political challenges, or it will be embracing them and seizing the new opportunities that the EU can bring in this field?

During this uncertain time, I am very glad that an initiative called the European Health Parliament exists bringing together 60 young leaders and fresh minds in the field of health from all around Europe. These diverse group formed by health care professionals, scientists, NGO advocates, lawyers, industry experts and even patients themselves was working days and nights trying to identify the most emerging issues in the field of health. It also engaged with policy makers and European and national stakeholders in order to develop five actionable policy recommendations and emphasize believes of the youth that the European Union must forge itself a stronger, more incisive role in improving the health and safety of EU citizens.

It is my great pleasure to introduce you the fruits of tremendous work done by 5 committees, namely:

1. **Data for Healthy societies**, chaired by **Lucia Medori**
2. **Disease, Prevention & Management**, chaired by **Bénédicte Faure**
3. **Innovation & Value**, chaired by **Anna Swierczyna**
4. **Health Literacy & Self-care**, chaired by **Urška Košir**
5. **Human Health & the Environment**, chaired by **Arianna Gamba**

In the following pages, you can find solutions and actions that reflect the vision of youth on the most emerging health challenges in Europe. There is still strong support for the European project, but it is no longer unconditional and we all need to make sure that the actions are meaningful and contribute to healthy societies, because health as the most precious commodity measures the overall welfare of population.

In the past, the history has always been shaped by power of youth and this time youth also does not stay behind! We are now calling for continued European cooperation in the health sector and we committed ourselves to make health and innovation a priority for Europe in the forthcoming years. The European Health Parliament is THE movement and to implement our ideas we need your support, because only together **#WeRun4Health**.

Antonio Tajani

European Parliament President

Dear Dr Gatialová,

Dear Members of the European Health Parliament,

Thank you for your engagement in building a healthier and more innovative Europe. You are the voice of thousands of young professionals across the healthcare sector. Digital technology has become an integral part of our daily lives: from transport to work to communications and study.

It is also changing how we take care of the sick. Digital infrastructure, advanced telemedicine, robotics and artificial intelligence are the new frontier of healthcare.

Improving the exchange of data and prevention is crucial to making healthcare systems more effective and accessible.

To exploit the potential of the digital revolution we should invest in training and learning. This is the only way to give patients and professionals what they need.

The Report on Health Technology Assessment adopted by the European Parliament last October goes in this direction. It calls for urgent investment in innovative technologies and joint clinical assessments.

The future of healthcare requires integration, patient empowerment and a dynamic role for professionals.

Patients should be at the centre of healthcare systems in all Member States.

To this end, we are proposing to ensure a health dimension in our next EU Budget. The European Parliament is asking for appropriate funding levels in the European Social Fund, Digital Europe and Horizon Europe Programmes.



In addition, we are requesting a specific health programme with a budget of 480 million euros.

EU healthcare system efficiency is our first challenge. For this, it is also important to foster synergies at Member State level.

Today, patients, researchers, healthcare professionals and policymakers have to join forces for a new health plan in all the European Union.

Your policy recommendation are an important contribution to this major debate.

To achieve this goal, we need your support.

Thanks for your engagement!

A handwritten signature in black ink that reads "Antonio Tajani".

Antonio Tajani

A large group of young professionals, approximately 40-50 individuals, are posed on a wide staircase. They are dressed in business-casual attire, including blazers, dresses, and shirts. The group is arranged in several rows, with some individuals standing on the stairs and others crouching or sitting at the bottom. The background features a building with a prominent glass and metal framework, suggesting a modern architectural style. The entire image is overlaid with a warm, yellowish-orange tint. The word "RECOMMENDATIONS" is centered in the middle of the image in a bold, white, sans-serif font.

RECOMMENDATIONS

MAKING EUROPE HEALTH LITERATE BY 2025:

Seven Actions to Promote Health Literacy and Self-Care in the Digital Era

Chair

Urška Košir

Vice-Chair

Lauriane Harrington

Members

Madalina Butuc

Eline Lubbes

Claudia Doldo

Rodolphe Guillemin

Ivana Paccoud

Weronika Kowalska

Ava Lloyd

Suvi Karuranga

Kimberly Feldewerth

Jose L. Sandoval



ENDORSEMENTS

The Committee would like to thank the following individuals and organisations for the continuous support, guidance, comments, and invaluable suggestions throughout the past six months. This policy brief is a result of collaboration, hard work, and dedication from the team members.

A big thank you to: Ms Bhasuri Ariyathilaka; Ms Nicola Bedlington; Dr Andrew Bottomley; Ms Jacqueline Bowman-Busato; Ms Karin Kadenbach; Ms Eva Kaili; Dr Heidi Maurer; Dr Jany Rademakers; Dr Kristine Sorensen; Ms Valentina Stramiello; Ms Susanna Van Tonder.

Thanks also go to: Third_i and Health Literacy Europe for endorsing our policy draft; MedTech Views for publishing our blog; and partners of EHP who made this journey possible.

Last but not least, thanks to all the participants who responded to our online survey.

Kristine Sørensen

Director of the Global Health Literacy Academy, Executive Chair of Health Literacy Europe and President of the International Health Literacy Association.



"Health literacy is on the European health agenda. I am convinced that the efforts and recommendations of the Committee on Health Literacy and Self-Care of European Health Parliament will help us embrace the health literacy divide and to ensure we leave no one behind. A proper response from professionals and organisations in the healthcare field considers people's functional, interactive and critical health literacy. We shall meet people where they are and build on their capabilities by making health accessible, understandable, appraisable, and applicable for all. Yes, let us together make Europe health-literate by 2025!"

Jacqueline Bowman-Busato

Policy-Impact Lead, Self-Care Initiative Europe
Principal, Third-i



"The Policy-Impact arm of the Self-Care Initiative Europe is delighted to have collaborated on this year's European Health Parliament Health Literacy and Self-Care Recommendations. Digital health literacy is an important enabler for the embedding and uptake of self-care, particularly in upcoming digital native generations. The very thorough work of the European Health Parliament Committee on Health Literacy and Self-Care has not only usefully contributed to the policy dialogue, but most importantly proposed some concrete actions which will help realise tangible results across policy sectors as well as geographic scope in the EU Member States. We very much look forward to continuing our joint efforts to make self-care a reality along the continuum in Europe and a measurement of resilient health ecosystems, with digital health literacy as a core element for sustainable uptake of self-care."

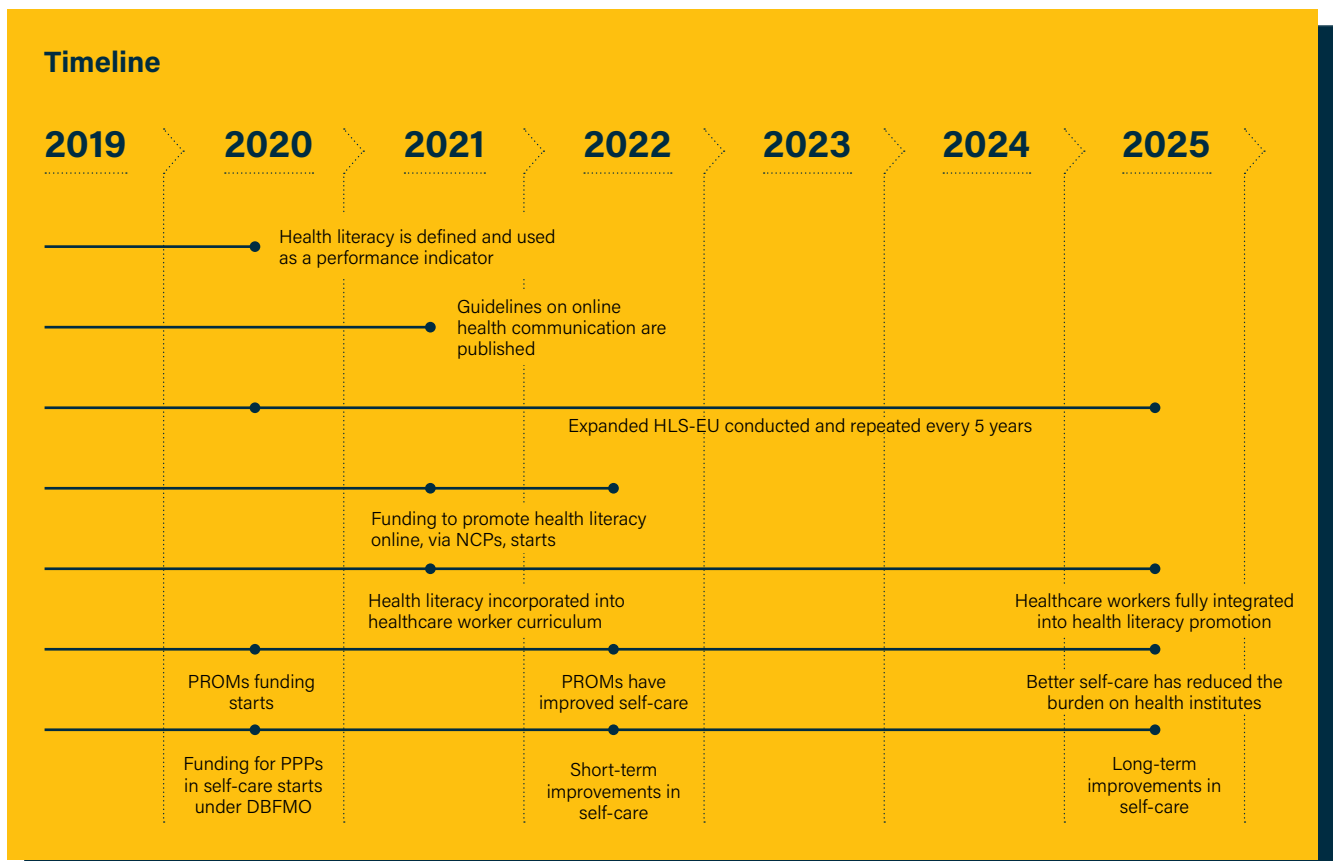
EXECUTIVE SUMMARY

Online health information is available almost anywhere, at any time, and is shared faster than ever. As consumers of health information in an increasingly digital world, we are faced with many challenges – where do we find reliable information and how do we appraise and apply it to prevent illness and promote self-care? How do we become more health literate and navigate the digital healthcare landscape?

In order to promote health literacy and self-care, the EU and its Member States need to work together to establish best practices for the accessible and reliable online communication of health information. This means implementing novel policies to improve:

- » **The availability of reliable health information via digital sources**
- » **Education of health professionals on health literacy, including digital aspects**
- » **Meaningful patient involvement in developing health literacy tools and methods**

Our seven policy recommendations are actionable, bring health policy into the digital sphere, and promote patient inclusiveness in their self-care.



INTRODUCTION

Citizens across Europe are continuously challenged to make healthy life choices, learn about their treatment options and understand their journey as patients. In order to do so, they need to be health literate. Health literacy is generally defined as people's knowledge, motivation and competency to access, understand, appraise, and apply health information in everyday life concerning healthcare, disease prevention and health promotion.¹ It is a key determinant of health, and lays the foundation for patient-centricity by enabling patients to play an active role in their own health and to consider their own self-care. Yet, close to 50% of the EU population reports below optimal levels of health literacy¹, with large discrepancies between countries assessed.²

An underexplored avenue to promote health literacy across the EU is digital media. In Europe, there are more smartphones than there are doctors per capita^{3,4} and a significant number of European citizens regularly consume health-related information via digital sources.⁵ However, the plethora of healthcare information freely available online may present complex and conflicting messages, making it hard to interpret, judge, and apply for self-care.⁶ A key example of this is the spread of vaccine hesitancy through social media.⁷

Some EU initiatives such as: IC-Health⁸ (Horizon 2020-funded initiative to improve digital health literacy of EU citizens); Eurobarometer survey (2014) on European's digital health literacy⁵; and the 2016 expert report on "Accelerating the Health Literacy Agenda in Europe"⁹ aim at addressing issues related to low health literacy. However, there are no existing EU-wide policies that focus on health literacy promotion via media and digital health.¹⁰

To align with the EU strategic health goals including the Europe 2020 strategy¹¹ and the eHealth Action Plan 2012–2020¹², to in turn promote good health among its citizens, an overarching EU strategy for health literacy is needed, with a specific focus on digital media.

"Health literacy is defined as people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in everyday life concerning healthcare, disease prevention and health promotion."¹¹



OUR APPROACH



In addition to expert consultation and a comprehensive review of the literature identifying the barriers to improving health literacy within the EU, the Committee on Health Literacy and Self-Care conducted an online survey asking European citizens about their understanding of health literacy; where they obtain relevant health information; whether they wish they could be more involved in the management of their health care; and what they think the EU could do to improve health literacy and promote self-care across its Member States.

The literature, consultation and survey results provided the framework upon which the Committee based our policy recommendations, which focus on three areas: (1) quality of information; (2) education and uptake of health literacy practices; and (3) patient-centred self-care.

"We developed an online survey and distributed it via social media channels. A total of 169 citizens (average age 28, range 18-64 years), from across 23 European countries responded. The results guided and informed this policy brief."

RECOMMENDATIONS



I. PRIORITISE HEALTH LITERACY AND SELF-CARE UNDER THE NEXT EUROPEAN COMMISSION

Adopt common definitions and include health literacy and self-care among the European Core Health Indicators (ECHI)

As Europe enters a new legislative term, it is paramount that all sectors employ the same definition of health literacy and self-care, as a continuum to enabling the sustainable embedding and uptake through all channels, including digital. We call on the European institutions to fulfil the following by the end of 2019:

- › Agree on common EU definitions of health literacy and self-care before the adoption of the next EU Strategic Plan.
- › Include health literacy and self-care as performance indicators in the list of ECHI.

II. QUALITY OF INFORMATION

As the volume and availability of health-related information is increasing, the poor reliability of this information makes it challenging to navigate. Improving the quality of this information and citizens' ability to critically assess it is therefore key. The Committee recommends the following policy actions to address this issue:

Establish guidelines for accessible and reliable online communication of health information

The Committee recommends the creation of a standardised set of best practice guidelines for effective health communication to the public. Conforming to these standards will be an easy indication to the public as to the reliability of a source's healthcare information as well as an appraisal method for expert reviewers.

The key components of these guidelines should check for accurate, evidence-based, up-to-date information, as well as language and format adapted for the lay audience. A similar self-certification method has been developed to promote best practices in the reporting of clinical research (CONSORT¹³), and epidemiology research (STROBE¹⁴).

The Committee recommends that the European Commission convenes an expert panel in early 2020 to develop these guidelines, which should be released and communicated by 2021.

European Core Health Indicators (ECHI) are a list of indicators that account for health and health systems overview across the EU. Some examples of ECHI are vaccination coverage in children, drug-related deaths, or hospital beds.²⁵

Promote and build on the European Health Literacy Survey

The European Health Literacy Survey (HLS-EU), first conducted in 2011 across eight Member States, revealed low health literacy and large discrepancies between countries. This is particularly evident in groups with a higher age and lower socioeconomic status¹⁵, which presents a public health challenge. An immediate and actionable solution is to expand the pivotal HLS-EU, in line with the following guidelines:

- › Expand the survey into all Member States;
- › Conduct the HLS-EU every five years to evaluate the effect of policy measurements;
- › Include questions on how citizens gather and assess health information;
- › Expand and adapt the survey for children and adolescents;
- › Adapt a digital version of the survey to cover a broader audience;
- › Add a section focusing specifically on digital health literacy;
- › Foster closer cooperation between the EU and WHO to strengthen health literacy measurement.

By supporting current efforts (e.g. Action Network on Measuring Population and Organisational Health Literacy (M-POHL Network¹⁶)), this initiative can have immediate impact by 2020.

III. EDUCATION AND UPTAKE OF HEALTH LITERACY PRACTICES

Although citizens are willing to actively improve their digital health literacy, the discussion remains largely within industry and expert circles¹⁷ and uptake across health professionals, doctors and the population remains a challenge. The Committee therefore recommends the following:

National Contact Points (NCPs) are independent organisations of different types (such as Universities, Ministries, etc.) based in all Member and Associated States. They provide multilingual support to citizens and aim to raise awareness on cross-border health care.²⁶

Leverage existing National Contact Points (NCPs) to promote health literacy online

The NCPs established in every Member State under the Cross-Border Healthcare Directive 2011/24/EU¹⁸, should be leveraged to support the uptake of health literacy via digital media by:

- › Training staff on the promotion of accessible and reliable healthcare information online as a means to increase health literacy and self-care, building on the guidelines referred to in recommendation #1 and local experience of the NCPs;
- › Strengthening cooperation and sharing of best practices on health literacy.

Funding to promote the above initiatives should be made available under Horizon Europe, Digital Europe and the European Social Fund+, as part of the upcoming Multiannual Financial Framework (2021-2027). An investment today would result in a sustainable output from 2021 onwards.

Develop health literacy as a professional skill in the health workforce

As new technologies are fast developing, providing adequate training and enhancing digital awareness for health professionals is crucial. Long-term investment in systemic changes such as educational programs for the health workforce will allow healthcare professionals to sustainably promote health literacy in their patients, across healthcare departments, for years to come. The Committee recommends that:

- › In collaboration with educational institutions and organisations within Member States, the European Agency for Health & Safety at Work develops and facilitates health literacy training for health professionals;
- › Healthcare professionals' curricula foster and incorporate evidence-based health literacy measurements and interventions;
- › The European institutions, in collaboration with national health literacy networks and Health Literacy Europe¹⁹, provide and facilitate digital platforms for knowledge exchange and knowledge transfer among the health workforce;

- › A centralised EU platform for sharing of existing and new health literacy tools, innovations and technologies among health professionals is established and funded by the European Commission.

IV. PATIENT-CENTRED SELF-CARE

Patient centricity lies at the core of health-related policies. The successful implementation and promotion of health literacy will empower patients and encourage the meaningful participation of citizens in health-promoting behaviour, resulting in the increased uptake of self-care and improved quality of care overall.

Create EU-wide standards in patient-reported outcome measures (PROMs)

Meaningful patient participation in health care improves health literacy and in turn, self-care. Digital health solutions using standardised PROMs will further promote self-care by monitoring of subjective outcomes (e.g. pain or depression). Achieving PROMs uniformity, together with advances in digital health, would promote the development of new health care models. These will translate into health benefits to EU citizens and greater economic efficiency and sustainability of EU health care systems

To reach PROM uniformity and avoid PROM-related data fragmentation, the Committee calls on the European Commission to form a “European Consensus Group on

Patient-reported outcome measures (PROMs) are self-reported questionnaires about health or quality of life. They can be used to monitor patients’ progress and allow for meaningful engagement in one’s self-care.²⁷



Patient-Reported Outcome Measures for Health Literacy and Self-Care”, a multinational, multi-stakeholder effort to include representatives from healthcare professionals, academics, patients, and industry.

This recommendation will immediately support the long-term initiatives to optimise PROM use. The expected long-term improvement in self-care will tangibly reduce the burden on healthcare institutes.²⁰

Establish public-private partnerships (PPPs) to facilitate a personalised approach to self-care using digital technologies

Co-creation of a personalised self-care plan using digital technologies for monitoring progress and care will become the norm in the years to come. Medical and technological advancements increasingly require people to manage complex medical tasks at home. Telemedicine (e.g. RENEWING HeALTH²¹) can reduce the burden on the health care system while simultaneously improving individuals’ health literacy and promoting self-care.

The Committee recommends that continuous funding under Digital Europe and Europe 2020 Strategy is made for PPPs, under the “Design-Build-Finance-Maintain-Operate” (DBFMO) contract²², for projects that will facilitate and promote the uptake of reliable digital health information by addressing patients’ individual needs.

Such PPPs allow the implementation of ambitious and highly impactful projects, by matching the resources of one stakeholder to the needs of another. This recommendation could therefore greatly improve self-care in Europe by 2025.

Our recommendations are actionable, bring health policies into the digital sphere, and put the patient in the driving seat by:

- › Securing access to reliable health information;
- › Promoting the education of health workforce;
- › And increasing meaningful patient participation.

CONCLUSIONS

A woman with short dark hair and glasses is speaking into a microphone. She is wearing a dark jacket over a light-colored shirt. The background is blurred, showing other people in a room.

Increasing health literacy improves citizens' health and wellbeing, decreases the burden on healthcare systems and reduces health inequalities.²³ Health-literate societies will therefore be healthier, prosperous, and more equitable.

Given that a vast majority of European citizens use the internet at least once per week,²⁴ digital health and media should become complementary tools to empower citizens and democratise healthcare across Europe. These policy recommendations set out to engage citizens, policymakers, healthcare professionals and other stakeholders in taking active steps to achieve the ambitious goal of making Europe health literate by 2025.

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PATHWAYS FOR A HEALTHY STATE OF MIND IN EUROPE

*Promoting Mental Wellbeing and Improving
Prevention and Care of Mental Ill Health in
the EU Digital Era*

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ENDORSEMENTS

The Committee would like to thank the following individuals and organisations for the continuous support, guidance, comments, and invaluable suggestions throughout the past six months. This policy brief is a result of collaboration, hard work, and dedication from the team members.

A big thank you to:

- › **Sirpa Pietikäinen**, Member of the European Parliament (Finland, EPP)
- › **The European Federation of Psychology Students' Associations (EFPSA)**
- › **Claudia Marinetti**, Director, Mental Health Europe
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Developmental psychologist, Adapei France (NGO for people with mental disabilities)



"I fully agree with the policy recommendations of the Committee on Disease Prevention and Management. The legislative proposals are very relevant and to the point. I am pleased with their work and quality of their analysis. In particular, I appreciate the attention that has been paid to investment in public awareness of mental health problems and in patient advocacy, as well as ensuring Health Technology Assessment (HTA) for eMental health apps. In order to make Europe a healthier place to live, we need to include "health" and also "mental health" in the EU agenda. To make that possible those policy recommendations should be seriously taken into consideration by European Commission and policymakers."

EXECUTIVE SUMMARY

Mental health is vital for individuals, families and communities. But mental ill health is not an incurable diagnosis: for people who develop mental health problems, recovery is the aim and an achievable outcome for all when given the right support – recovery meaning living with and managing mental health problems, while having control over one's own life.

The recommendations herewith aim to **promote a positive shift in attitudes around mental health problems** in order to move towards **better societal understanding**, promotion of mental wellbeing, prevention of ill health, and **increased public investment**.

Because most mental health problems are interlinked with the societal and structural environments we live in, and are dictated by psycho-emotional responses to these experiences, various sectors and stakeholders have a role to play in responding to mental health in Europe, beyond the healthcare sector.

Mental ill health and mental health problems pose an undeniable challenge to Europe's population, societies and economies, which **requires political prioritisation and the mobilisation of resources**. Human rights should constitute a primary argument for investment and action.



INTRODUCTION

In the context of international political attention on mental health, with mental health being integrated for the first time alongside chronic physical health at the United Nations High-Level Meeting on Non-Communicable Diseases in September 2018, and being an integral part of discussions at the World Economic Forum 2019, we have decided to focus our work on the political response to mental ill health.

Over the past six months, we have explored the topic of mental health in Europe. Our committee consulted and held discussions with experts in the field and with patients. Furthermore, we conducted a comprehensive literature review of the current situation in European countries, mapping existing evidence and recommendations. We decided to address important areas where action by the European Union could add value, not only by supporting Member States' activities, but also by creating "an innovative and European way" of promoting mental wellbeing and driving a better future for citizens.

While it affects a large proportion of the population, **mental ill health remains a huge taboo** in our current societies and often leads to social stigmatisation.¹²

Mental health problems can affect everyone at some point during their lifetime. As young professionals working in the healthcare field, we believe that **societal acceptance is key** to bringing change. We believe that such a shift in societies and mentalities would benefit from a terminology change, whereby mental ill health is not considered as one single group of diseases, but instead as "mental health problems". Tackling these mental health problems requires **a holistic, psychosocial approach** looking at physical, social, and structural environments. **People-centricity is crucial**, and it should be emphasised that preventing and caring for mental ill health does not happen in the healthcare sector

"We all have mental health in the same way that we all have physical health. It's OK to have depression, it's OK to have anxiety, it's OK to have adjustment disorder."

– Prince Harry, Duke of Sussex, Earl of Dumbarton and Baron Kilkeel

only, but that a whole societal and environmental approach is required.

More importantly, a more **positive narrative should be used in relation to mental health**, talking about "**mental wellbeing**" and "**healthy states of mind**" – which are important patterns of good health and a healthy life.

About Mental Health

- › One out of six people in the EU – accounting for over 84 million people – have a mental health problem.³
- › One in five adolescents in Europe is affected by at least one mental health problem in any given year.⁴
- › The economic impact of mental health problems is estimated at more than €600 billion across the EU, including healthcare costs (about 1.3% of the EU's GDP, or €190 billion) and social security programmes (1.2% of the EU's GDP, or €170 billion).⁵
- › Economic loss from reduced employment and productivity is estimated at 1.6% of GDP, or €260 billion.⁶
- › Over 84,000 people died due to mental health problems in 2015 in the EU.⁷

RECOMMENDATIONS

"We can no longer afford to be silenced by stigma or stymied by misguided ideas that portray these conditions as a matter of weakness or moral failing."

– Lady Gaga

Concrete actions from European institutions can help address the mental ill health challenges in Europe:

- › **Investing in awareness of positive mental health, mental health problems and de-stigmatisation;**
- › **Adopting a societal and environmental approach to promotion, prevention and care of mental health problems;**
- › **Increasing investment and funding towards “mentally healthy” societies.**

I. INVESTING IN PUBLIC AWARENESS OF POSITIVE MENTAL HEALTH, MENTAL HEALTH PROBLEMS AND DE-STIGMATISATION

“It is OK not to be OK”: Mental health is a state of mind related to how we think and feel, to the issues and barriers we face. Mental ill health is common and is not a personal failure. Despite the fact that many of us are affected, there is a strong social stigma attached to mental ill health, which can worsen one's problems; it might delay or impede efforts to seek help, effective treatment and recovery, as well as cause clinical complications⁸, but it can also hamper policy action. Stereotypical or inaccurate comments about mental health problems contribute to this situation.

Awareness and understanding together represent the first step towards acceptance and, therefore, more inclusive societies. **Promoting positive conversations and education about mental health lays the groundwork for understanding, prevention and appropriate intervention.**⁹

Use the potential of digital tools to support mental health awareness online

Digitalisation can present challenges to mental wellbeing, e.g. continuously checking social media; though, at the same time, it can provide opportunities to improve mental health in the form of e-mental health tools and digital solutions. An increase in mental health problems has been observed in parallel with the digital era and today's digital society, particularly among young people. On the positive side, **one of the opportunities that digitalisation brings is e-tools that can have tremendous impact for awareness-raising online**, reaching wide audiences and breaking the taboo on mental ill health. Because greater societal acceptance is crucial to progress the response to mental health, digital platforms and social media networks should play a role in order to inform and educate the general public about mental health and contribute to more supportive environments and free of stigmatisation of people with mental health problems.

Establish an online EU platform with testimonies from high-level public figures and opinion leaders who speak up about mental health

Showcasing public figures (e.g. from sport, entertainment, business or politics) that openly speak up about mental health can contribute to breaking taboos about mental health. **Role models are needed to change the conversation and tackle stigma around mental ill health.** An excellent example is the Heads Together initiative in the United Kingdom, where the royal family uses its high profile to create awareness about mental health and steer the public debate towards more acceptance of mental health.¹⁰ A European online platform could pave the way to more acceptance and more

open debates about mental health. It could also be a tool to showcase good practices from Member States, but also to highlight particular public and private entities that encourage an open debate about mental wellbeing and de-stigmatisation, as well as encouraging upscaling of best practices.

Set up an EU schoolteachers' awareness scheme, "Train the trainers", for educators from primary to high school settings

Talking about mental health with children is a first step to raise awareness, educate and prevent problems later on in life; it helps children understand that they can ask for help when faced with emotional difficulties, and that they should not be ashamed of talking about their state of mind or that they can support a friend or family member with issues. It can also help prevent bullying, destructive behaviours or anxiety in school settings. During adolescence, awareness about mental health is similarly essential. During the teen years, mental health is especially vulnerable and requires supportive environments, including at home. Peer-to-peer education and similar school-based interventions have shown to contribute positively to bringing about understanding and awareness¹¹, including whole-school approaches delivering social and emotional learning programmes. A systematic approach, oriented towards school teachers in primary, secondary and high school education settings, could bring significant outcomes. We recommend that the EU supports the development of an EU schoolteachers' awareness scheme which would **empower education professionals** and give them the tools to inform and educate pupils about mental wellbeing and ill health; in place across all Member States, it would nonetheless be adapted to the specificities of each national education system. The content and format of such a training scheme should be defined by a consortium of experts from academia, patient representatives and advocacy organisations actively involved in awareness and education projects.

The EU should support and invest in **programmes for Continuous Professional Development** and the integration of transversal skills within national curricula for teachers, professors and health professionals in order to ensure understanding of mental health, as well as knowledge of how to promote mental wellbeing and how to support people with mental health problems.

II. ADOPTING A SOCIETAL AND ENVIRONMENTAL APPROACH TO PREVENTION AND CARE OF MENTAL HEALTH PROBLEMS

Mental wellbeing and prevention of mental ill health start in our daily life. While there are some genetic predispositions associated with mental health problems, evidence shows that the majority of risk factors relate to our environment (e.g. at school, work and home).^{12,13} Workplaces that promote mental wellbeing should be the standard. Particular attention should also be given to preventing mental ill health amongst the youth population and supporting at-risk or affected adolescents and young adults, who are at critical stages of life for mental health and wellbeing. To complement existing mental health care approaches, interventions outside the regular care sector should be explored.

Create an EU reward system for companies taking active steps to ensure a healthy environment for mental wellbeing at the workplace

Employers have a major role to play in managing mental health at work. They have access to a large segment of the population who spend significant time at work (1/3 of their adult life)¹⁴ and can be reached repeatedly at low cost. An EU label for companies performing well could create an incentive mechanism for better mental health at the workplace. Companies and trade unions could be rewarded for their good practices in observing WHO guidance on mental health at the workplace¹⁵ and in utilising the tools developed by the EU Joint Action CHRODIS Plus¹⁶ to take measures to prevent work-related stress and mental ill health, promote mental wellbeing and integrate workers with mental health problems via necessary adjustment measures. Investing in such measures is an economical consideration that employers can make, as productivity is directly related to mental wellbeing and increasing mental wellbeing has shown to reduce work absence.¹⁷ **An EU label would encourage employers to go beyond legal minimums and give them public recognition** for their good practices.

"An EU label would encourage employers to go beyond legal minimums and give them public recognition for their good practices."

In parallel with incentivisation models aimed to ensure good mental wellbeing at the workplace, EU legislation for transparent and predictable working conditions remains key.

Invest in the future: include specific actions on mental health promotion, wellbeing and care for the youth population in the next EU programmes for action on health

Young people are the future of Europe – and also one of the key at-risk population groups for mental ill health. The prevalence of mental and behavioural health problems in adolescents at population level in Europe is high and increasing.¹⁸ A large proportion of the EU adolescent population lives with or has experienced a form of mental ill health. Yet, good mental health during youth and young adulthood is essential for future personal development. Poor mental health in children and adolescents has an impact on educational outcomes and future integration in the labour market.¹⁹ Meanwhile, half of all adult mental health disorders appear before the age of 14²⁰ and children whose parents suffer from mental health problems are up to two and a half times more likely to experience poorer mental health outcomes than their peers.²¹ We recommend that EU action in the health domain, including in the context of the European Social Fund Plus (ESF+), allows for interventions that specifically address the needs of the younger generations. In particular, EU funds should: allow for further **research into the impact of social media and the increased use of digital tools by new generations on mental health**; allow for the implementation of effective interventions to prevent mental ill health in the youth population; and **support countries in setting up effective parenting and home-visiting programmes** that promote infant and maternal mental health, allowing every child to have a good start in life, reducing risks of mental ill health in adolescence and adulthood.

Integrate implementation research projects into Horizon Europe in order to increase uptake of nature-based interventions as complementary therapies for mental health prevention and care

Research and studies are increasingly confirming the benefits of non-pharmaceutical therapies building on societal or environmental approaches, such as nature-based interventions (e.g. nature walks and physical activity in general), to improve mental wellbeing and prevent mental ill health (primary prevention), alleviate risks and elevate mental health in people

presenting symptoms of mental health problems (secondary prevention), or help support and maintain recovery.^{22,23} Building on the pioneering example of several EU countries including England and Scotland^{24,25}, national healthcare systems should integrate better those nature-based measures, commonly referred to as “nature prescriptions”, and healthcare professionals should be incentivised to prescribe them more systematically to supplement conventional medicines.

We recommend that Horizon Europe supports: 1) **implementation research to allow transfer and scalability of existing practices across EU countries**, including in urban settings, as well as 2) **increased research into nature-based interventions as a mechanism for addressing mental health**, to improve understanding of the conditions that deliver the best outcomes from such interventions.

Enable Health Technology Assessment (HTA) for e-mental health apps

Innovative and high-quality e-mental health technologies are bringing breakthrough solutions to prevent and care for mental health problems.²⁶ They have the potential to complement psychological approaches, conventional medicines and other interventions and can be implemented in healthcare practice with significant cost savings for healthcare systems. However, **there is currently neither control nor clinical evaluation of these e-mental health tools.** An EU framework to ensure quality, efficiency and safety would protect European citizens from unsafe products (#EUprotects). We recommend that the European Commission **integrates digital health applications and technologies in the EU Health Technology Assessment (HTA) framework** or sets up a specific evaluation framework for such e-technologies, harmonised at European level, to ensure that efficient, secure tools reach patients. The human aspect of care with a doctor-patient relationship should nevertheless remain an integral part of the treatment pathway. Measures should be taken to monitor use and counter any negative effects on people's mental health of using digital solutions.

In parallel, Member States should make the necessary policy reforms and measures to guarantee availability and patient access, including via the implementation of national e-mental health strategies, which encompass infrastructure, skills and adequate reimbursement on the national healthcare system of e-technologies that have been positively assessed.

"Good mental health during youth and young adulthood is essential for future personal development."

Ensure equality of social protection for citizens with mental health problems across Europe and universal access to quality mental health services

Currently, people with mental health problems face structural barriers to appropriate care; one of them relates to access to health insurance. This exacerbates societal stigma around mental health and deters people with mental health problems from opening up about their issues and seeking appropriate care. **Every EU citizen is entitled to fair and equitable access to insurance and should be guaranteed the same level of health protection**, no matter their country of residence or mental or physical health status. This is a principle of equal human rights and non-discrimination. EU anti-discrimination legislation and national frameworks should guarantee universal health coverage for all EU citizens and provide measures to ensure that pension schemes and insurance systems across Europe are not discriminatory towards people who live with or have experienced a mental health problem. A surveillance system should be put in place to ensure compliance with applicable laws.

In addition, the EU and Member States should **effectively guarantee universal access to quality mental health services**, in particular with regards to child and adolescent mental health services.

III. INCREASE INVESTMENT AND FUNDING FOR “MENTALLY HEALTHY” SOCIETIES

Good mental health is important for economic growth and social development in Europe. Mental ill health has a tremendous impact on the EU economy, as it directly affects workforce productivity.²⁷ Currently, the response to mental health and levels of dedicated funding within national healthcare systems vary greatly across EU countries, but it can be observed that **funding is overall insufficient to efficiently address the mental health challenge in Europe**. The proportion of total health system expenditure allocated to mental health prevention and care is often very small; many countries do not even have mental health policies in place, or face shortages of specialist healthcare professionals, while political commitment to improving the situation remains at a low level.²⁸

Increasing investment is a prerequisite for productive, healthy societies and sustainable EU economies.

The European Commission should encourage the development of national mental health promotion and protection action plans via the EU semester recommendations

The need for action and the economic case for investing in mental health promotion and prevention of ill health are clearly outlined by various evidence-based studies, including the EU/OECD *Health at a Glance* report 2018. National action plans are effective means to plan, implement and monitor interventions to deliver tangible results. We recommend that the European Commission encourages Member States to **develop mental health promotion, protection and prevention action plans**, using the opportunity of the country-specific recommendations part of the EU semester process and in its capacity as a facilitator of the EU Steering Group on Promotion and Prevention²⁹, to scale up action across Europe.

Explore the potential of EU public-private partnerships to steer investment in transferring and scaling up identified good practices for mental health promotion and care across Europe

Many good practices exist and are identified as such, but there is a **major gap in implementation**. Part of the problem lies in the lack of long-term funding to ensure a sustainable scalability of good practices over time. **EU Public-Private Partnerships** (PPP) with clear rules on transparency and conflicts of interest for engagement of the private sector could help address this gap. We recommend that the European Commission initiates an EU PPP bringing EU funds together with philanthropic entities/foundations and academia to **develop a sustainable funding model for long-term investment in the transfer of good practices in mental health prevention and care** across Europe.

"Every EU citizen is entitled to fair and equitable access to insurance and should be guaranteed the same level of health protection."

CONCLUSIONS

A photograph of five people in a meeting, overlaid with a blue tint. The group consists of three men and two women, all dressed in business attire. They are seated around a table, with some holding papers and pens, suggesting a collaborative discussion or workshop. The background shows a modern interior with large windows and a glass door.

People's physical and mental wellbeing go hand in hand with economic growth and sustainability. Mentally healthy societies are a prerequisite for prosperity. Promoting good mental health and wellbeing at a population level should be standard practice. Evidence exists on how to improve prevention and care of mental ill health; some EU countries are implementing pioneering initiatives, while the EU also has the capacity and the potential to generate and deliver on innovative approaches to effectively respond to mental health in Europe. It is now time for political leadership and investment in order to protect Europeans and future generations.

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CONNECT – SHARE – PROTECT

Three Priorities for an EU Health Data Ecosystem

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ENDORSEMENTS

Roberto Bertollini

*President of Health First Europe
Former WHO representative to the EU*



"Health data exchange and digital health have the potential to promote a philosophy where citizens are put first through innovation. In order to move towards a system what matters most to patients, the EU has to strike the right balance between fostering innovation and protecting patients' privacy and safety. More investments allocated to health are needed in order to build on the existing Digital Services Infrastructures and foster the crucial role of health settings in the uptake of digital solutions and modern data infrastructures. I believe the recommendations from the European Health Parliament's Committee on Data for Healthy Societies provide valuable guidelines for the next Commissions and upcoming European Parliament to shape an effective and trustworthy data ecosystem, focused on what matters most to a society: citizens' health and safety!"

Johan Prévot

*Executive Director – IPOPI
– International Patient
Organisation for Primary
Immunodeficiencies*



"I welcome the initiative of the European Health Parliament, and in particular the policy recommendations presented by the Committee on Data for Healthy Societies, which are very relevant for building a European data ecosystem beneficial for all our citizens. I appreciate the attention given to data-driven research and expertise exchange to improve patients' outcomes. European Reference Networks (ERNs) on rare diseases provide an excellent success story of EU cooperation, where patients and clinicians work together for better care. For the benefit of research and diagnosis of complex conditions such as primary immunodeficiencies, ERNs should be expanded and consolidated at national level to facilitate discussion on rare conditions."

Antonio Tajani

*President of the European
Parliament (EPP, Italy)*



"The European Health Parliament tackles the next challenge coming from digital health which has become an integral part of our daily lives: digital infrastructure, advanced telemedicine, robotics and artificial intelligence are the new frontier of healthcare. The key is improving the exchange of data and prevention to make healthcare systems more effective and accessible. The Committee on Data for Healthy Societies has proposed an important contribution to this debate with its policy recommendations highlighting the importance of integration and patient empowerment as the centre of the healthcare systems for a new health plan in all the European Union."

Sirpa Pietikäinen

*Member of the European
Parliament (S&D, Finland)*



"We need EU-regulation to ensure the interoperability of patient and health data systems. The data ownership has to be with the patients, with only European insurers, or those that the patient specifically grants permission to, having access to their data. A pin-number-secured insurance health card, with a chip, that works like a credit card, could be the means to create a safeguard for this data."

Alojz Peterle

*Member of the European Parliament
(EPP, Slovenia)*



"Digital and data revolution in care can support more integrated services, better patient safety, improved quality and access to care everywhere, as well as strengthen relationships with health carers. If European policymakers play their cards right, we can strike the right balance between patients' privacy and open data for better research and improved healthcare outcomes. I am happy to support the recommendations of the European Health Parliament on Data for Healthy Societies since I believe that they provide a suitable roadmap for the health data challenges that European countries have to face together."

José Inácio Faria

*Member of the European
Parliament (EPP, Portugal)*



"As digitalisation of healthcare matures, we understand the potential of ICT and the need for high-quality data. These recommendations develop this idea further by acknowledging the responsibility of stakeholders in trust, transparency and value communication of the systems. For interoperability to become a reality, data models need to converge, and for that to happen there is an urgent need for broad European consensus on data taxonomy. Also, ICT literacy needs to bind to health literacy as patient involvement will be paramount in the development of eHealth and mHealth. These tools are the window for actual continuity of care: anytime, anywhere, in the palm of our hand."

Heinz K. Becker
Member of the European Parliament (EPP, Austria)



"In my political work in the European Parliament I am putting a special focus on representing the interests of senior citizens and I am, at the same time, consequently following the demand of generations justice for the youngers and the elders in our society. I actively work in the Parliamentary Intergroup of Active Ageing and fight to make one principle the leading paradigm in health policies: Life Time Healthy Ageing – beginning in early child ages and uninterrupted until highest ages. Believing that this concept must be accompanied by making prevention and early diagnosis a political priority in Europe it is evident that we need – data! Therefore, I support the three pillars concept of CONNECTING + SHARING + PROTECTING presented by the European Health Parliament."

Dipak Kalra
*President, The European Institute for Innovation through Health Data (i~HD)
Professor of Health Informatics, UCL*



"I would like to warmly congratulate the European Health Parliament for prioritising this call to action on creating a strong European health data ecosystem. Its analysis covers the most important challenges that urgently need to be addressed in order to scale up the availability of high-quality health data and its trustworthy use to improve healthcare, accelerate research and empower citizens. I would like to personally endorse these recommendations and add my backing to this call to action. Policy makers and decision makers at EU and national levels must now work alongside all other health stakeholders to define the concrete steps needed, per recommendation, to realise this vision."

EXECUTIVE SUMMARY

Health data is essential to trigger digital innovation and foster disease prevention and care. This comes with unprecedented challenges and opportunities. We call for the EU and its countries to build a data ecosystem able to promote healthy societies by:

1. **CONNECTING** data infrastructures and fostering digital skills
2. **SHARING** data for research
3. **PROTECTING** citizens' data and promoting data fairness

Two ingredients are essential for making those three pillars steady: EU leadership and coordination and a patient-centric approach.



INTRODUCTION

The digital era is rapidly reshaping the ways we perform, receive and perceive health and healthcare. Commonplace consumer technologies, such as smartphones and watches, are being equipped to continuously measure and analyse our health, enabling a revolutionary quantification of our health. The amount of health information generated digitally across socio-cultural domains is unprecedented. Despite the self-evident public health potential of analysing such information, a fast and uncontrolled emergence of health data carries risks that require careful consideration. Lacking interoperability, inadequate infrastructures and risk of misuse are just a few of the challenges that digital societies have to face and solve.

Despite challenges, health data can be utilised for many beneficial purposes: they can be used by individuals to get insights about their health, reduce harm and prevent diseases; they can be used by physicians to fill health record gaps and conduct informed consultations; they can be used by research institutes to enable scientific discoveries; and they can be used by health providers to offer personalised services. To allow this potential to be reached, it is essential to foster data-driven innovation, while ensuring adequate mitigation against privacy risks and misuse.

While the EU has always been at the forefront of breaking down barriers and enabling cooperation and innovation¹, the era of digitalisation and “big data” requires an ecosystem that is not only open, but most importantly, trustworthy and beneficial for all. We need an environment of:

- › **adequate data infrastructures and digital skills;**
- › **responsible data sharing for research;**
- › **ethical safeguarding and appropriate data security.**

We believe that the EU needs to show leadership in coordinating actions on eHealth, whereby data-driven innovation is the first crucial step towards ensuring that our health data is actually used to improve the health of our societies.

"The amount of health information generated digitally across socio-cultural domains is unprecedented."



RECOMMENDATIONS

I. DATA INVOLVES INFRASTRUCTURE; IT IS WORTH CONNECTING AND UPSKILLING

The European digital health ecosystem is a fragmented one. It involves a large variety of stakeholders, data and IT infrastructures. Patients' data is siloed in different systems and heterogenous formats. The health workforce across Europe and beyond generally lacks the digital skills to implement the changes needed to support the move toward interoperability of health systems. Overall, the digital divide across Europe has been substantially reduced over the last decade, however, the gap remains far from closed. In order to tackle this fragmentation and give citizens greater access to and control over their health data, policymakers should focus on: interoperability, common standards, digital skills and new tools to gain insights from emerging types of data. Therefore, building on the existing policy framework, the European Commission, the Member States and the European Parliament should:

Refine the European Digital Health Interoperability Framework

- › **Broadening the scope of cross-border exchange of health data and fostering the role of the eHealth Network:** building on the EU actions on electronic health records (EHR) and the related standard formats², new datasets should be promoted by the eHealth Network for cross-border electronic exchange of patients' data. Furthermore, the role of the eHealth Network in coordinating national approaches to the use of cloud computing in healthcare systems should be enhanced.³
- › **Harmonising EHR data models:** much has been done for the standardisation of health data exchanges, but the way this data is stored varies greatly across EU countries. Promoting the harmonisation of data models for EHR



(meaning the way data is structured and stored) would lead to a more competitive and unified market for EHR software and ultimately foster cross-border exchange of data.

- › **Create a Single Healthcare Identifier for professionals:** all healthcare transactions found in EHRs and all ePrescriptions should be linked to a single identifier of healthcare professionals, along with their institution. This single identifier, when combined with EHRs, should help to better follow patients' pathways by allowing to see *who* (which provider) provided the care at which *point in time*, and also by facilitating communication exchange among healthcare professionals for a particular patient. A Single Healthcare Identifier repository should be openly accessible to patients and other healthcare providers, as well as paying and regulatory bodies. The identifier should include detailed information, such as the medical specialities or the languages spoken by the provider.⁴ The Commission should consider how this identifier can build on existing initiatives aiming at creating healthcare professional databases (e.g. European Professional Card).⁵
- › **Rethinking healthcare financial model for the digital age:** healthcare systems should address data infrastructure challenges and costs by translating digital benefits and connectivity into value for money; at the same time, they should assess which investments will do the most to save lives, reduce costs, improve quality and enhance equity.

Foster the healthcare workforce's digital and data skills through regular training and the integration of new professional profiles

It is crucial that healthcare stakeholders possess sufficient skills and knowledge to make the health data ecosystem a reality. By improving the digital skills of those involved (e.g. physicians, nurses, social workers, health managers), we can enable them to identify better ways to collect and share health data to deliver better outcomes, leaving more to the care of the patients rather than to data input, and ensuring solutions meet their needs.⁶ Fostering digital and data skills can be achieved by:

- › promoting training to foster data and artificial intelligence literacy, both in medical curricula at universities and at a professional level
- › integrating digital health specialists into healthcare systems and hospital management (e.g. medical scribes, coders, clinical documentation specialists, data scientists, app developers).⁷

Promote the use of open standards

As the number of mobile health applications and wearable solutions increases, practices to support open data standards are already being implemented. By removing barriers between innovators, open source promotes a free exchange of ideas within a community to drive creative, scientific and technological advancement. HL7 FHIR interoperability protocol is a good example of this, by allowing start-up companies with little resources to connect with existing infrastructures.⁸ The EU should encourage healthcare stakeholders to use standards that are publicly accessible.

Revamp the EU taskforce on eHealth to address emerging types of data in healthcare and ultimately support forward-thinking solutions

A taskforce between relevant Directorates-General in the European Commission should continue⁹ to pool efforts on digital health while exploring the emergence of new types of data, such as Patient-Generated Health Data (PGHD). The initiative should gather resources to bridge digital, research and health domains, while promoting existing forward-thinking solutions to use emerging types of data. These solutions should include interoperability protocols and mobile kits

designed to house health and wellbeing apps, to collate their data and be connected to a healthcare setting. By covering allergies, immunisations, lab results, medications and vitals, health data and mobile kits can help people live better while supporting healthcare systems in tackling the growing demand for care.

II. DATA SAVES LIVES; IT IS WORTH SHARING

As digitalisation penetrates all levels and domains of daily living, the amount of health-relevant information collected and stored across sectors is beyond comprehension. While the benefits of using such data for advancing research are significant (e.g. from finding new cures to delivering personalised medicine), much of this information remains unused, fragmented and within inaccessible infrastructures. Changing this requires a multi-level and multi-stakeholder approach that facilitates the creation of trustworthy and mutually beneficial data exchange for research. The following recommendations target the incentivisation of data flows between research institutes and three key data-holder groups:

- › the private sector
- › the public sector
- › individuals (whether these are patients or care providers).

As part of this, the EU and its Member States should encourage the flow of data between key stakeholders and academia or research institutions by targeting three principles: trust, transparency and value communication (i.e. those who share data for health research purposes should have access to easy-to-understand feedback on the output/impact of resulting research). At the same time, patients' privacy, preferences and inputs should be placed at the very heart of data collection and use for research.¹⁰ Therefore, building on the existing policy framework, the European Commission, the Member States and the European Parliament should:

"The EU and its Member States should encourage the flow of data between key stakeholders and academia or research institutions by targeting three principles: trust, transparency and value communication."

Encourage industry to participate in data sharing by promoting trust and transparency measures while unifying research data repositories

In the context of health research, pharmaceutical companies or health technology producers generate a large amount of clinical data to underpin learnings related to clinical conditions. Hesitancy in sharing this data remains, both among industry stakeholders themselves, as well as between them and academic research centres. Building on the European Open Science Cloud (EOSC)¹¹ and successful public-private partnerships such as the Innovative Medicines Initiative, scepticism in sharing should be addressed by fostering trust and transparency. Data access should be provided to the researchers for the agreed upon project only, while progress reports on the research should circulate among relevant data providers. Each industry stakeholder may have only a fragmented data set due to limited resources; facilitating data access upon agreement among members of the repository should avoid duplication of resources invested and create reimbursement value propositions from the research institutes.¹²

Clarify and upgrade GDPR framework for health data, going beyond consent and focusing on patients' involvement

Uncertainty over data sharing and use can hinder the research potential of health information. The public sector should engage in setting a new agenda to better safeguard public trust to enable the sharing of health data with researchers. While the General Data Protection Regulation (GDPR) is already an achievement in the protection of health data, further clarifications on its implementation in the healthcare sector are needed. There is still confusion around the current rules for secondary use of data and patients' consent, as well as a lack of detailed definitions for some key concepts, creating the potential for differences in implementation.¹³ Last but not least, consent is not enough for building trust and understanding around data sharing and its advantages. Patients' participation in data sharing should be expanded: patients should be involved across all points of the data cycle, not only through dynamic consent, but also in the curation and governance of health data platforms.

Develop new European Reference Networks (ERNs) and consolidate their model to overcome geographical differences and gaps in expertise

ERNs on rare diseases provide an excellent ecosystem where patients and clinicians work together for better care and research. To foster exchange of expertise across borders, and for the benefit of research, European Reference Networks (ERNs) should be expanded and consolidated at national level to facilitate discussion on complex conditions.¹⁴ The newly established European Platform on Rare Diseases Registration¹⁵ will be valuable for ERN development, allowing them to make use of anonymised information from a large pool of patients and offer better treatment to those in need.

Facilitate the sharing of patients' data by building a European framework for health data donation and by promoting value feedback loops

- › The EU, together with its Member States, should create a **European framework for post-mortem health data donation** to allow patients to share data comfortably (meaning respecting their preferences and protecting their privacy) after death. Citizens willing to donate their health data should be able to 'opt-in', making their information available post-mortality within health data repositories accessible for research purposes. This patient data should be pseudonymised and protected under GDPR. Within this framework, individuals could provide informed consent for their data to be used, while personalising their data sharing.¹⁶ Just as for organ donation, people should be able to indicate which data can be shared (e.g. removing sensitive data on mental health issues or sexually transmitted diseases), for how long, for which research purposes, and to choose between one-off use or limited multiple uses.
- › The creation of a European framework for health data donation should be accompanied by the creation of **common standards on anonymity in data**, while ensuring a limited impact on the scientific value of the data.
- › All major health research communication channels (e.g. scientific journals) should be incentivised to introduce free-to-access "**lay summaries**" of published research, **addressed to patients**, as well as caregivers that are not necessarily acquainted with scientific terminology and complex methodologies. Beyond that, those summaries should be additionally published in the languages of the

regions in which the research was conducted. This is an essential step for building trust and transparency, while enabling patients to appraise the value of their data for society, hopefully creating a more engaged data flow environment between European citizens and research institutes.¹⁷

Launch an awareness campaign to explain the benefits of data sharing

EU Member States should tackle the lack of awareness and limited interest in data sharing through public campaigns; these would explain the advantages of safe data sharing for public and population health, digital health engagement, and net new knowledge discovery, while putting the challenges of privacy and cybersecurity into an appropriate perspective.

III. DATA NEEDS TRUST; IT IS WORTH TACKLING MISUSE AND PROMOTING DATA FAIRNESS

The amount of data currently generated is fuelling a new era of technologies which, in the wake of recent data scandals, can only succeed by enhancing users' trust and by applying targeted policy solutions to tackle the real problems. While cybersecurity and privacy breaches are recognised as critical barriers to making health data more accessible, transformative technologies like cloud computing and artificial intelligence (AI) continue to evolve and are inherently fuelled by data. To make this into a success story, it is important that we work towards creating partnerships that embrace a common vision of the future of data-driven healthcare systems, tackling data misuses and fostering ethical behaviour. Therefore, the European Commission, the Member States and the European Parliament should:

Boost stakeholder dialogue and cooperation to develop secure tools against data breaches and cyberattacks

Public awareness of the rights and opportunities of sharing data should be complemented with a transparent and visible partnership to promote health-related cybersecurity standards. There should be full transparency around access and use of patients' data through the implementation of appropriate safe and innovative technologies (e.g. blockchain). Voluntary and real-time sharing of actionable cyber threat information between governments, businesses and academia should be in place to collaboratively prevent and mitigate cyberattacks.

Release EU guidelines on the ethics of data access and use in healthcare, also including an assessment of the ethical implications of big data and AI applications

European citizens and businesses need guidelines governing the ethical implications of AI, the purposes of research and access to patient data. In light of the AI Ethics Guidelines presented by the European Commission's High Level Expert Group on AI¹⁸, the EU should go beyond a one-size-fits-all approach. The Commission should tailor its ethical guidelines to the sensitivities of different AI applications, which is especially important in the healthcare sector. Those tailor-made guidelines should assess the risks of data misuse and algorithmic bias in the digital healthcare industry, and how that affects patients and their rights (i.e. discrimination in data-supported decision making, from recruitment to insurance services). They should also consider accountability and the ability to explain AI applications (from the data sets used for training to the end results).¹⁹ Ultimately, those measures should ensure that data fairness is in place, meaning that personal data is handled in ways that people would reasonably expect, and not used in ways that could cause disparities or affect them adversely.²⁰

Promote EU-wide codes of conduct for data-driven technologies and patient data protection

The Commission should support healthcare stakeholders in setting up principles for ethical, responsible and transparent data usage, while fostering a higher level of harmonisation and legal certainty for data rules across the EU. A self-regulatory code of conduct would be a crucial tool in ensuring that data protection of EU citizens is guaranteed when they make use of eHealth systems (especially cloud services).²¹ This code of conduct should also lead the industry to responsible creation of AI solutions, ensuring fairness, inclusivity, accountability and transparency for all involved (keeping in mind the importance of lay language and algorithms to be understood or reviewed by clinicians or regulators). This would contribute to an environment of trust and create a high default level of data protection, especially in the European cloud market.

CONCLUSIONS



Health and lifestyle data generated by numerous sources is rapidly expanding. The EU can and should break data siloes and create an ecosystem that connects and protects, while fostering the growth of digital health technologies and data-driven innovations. It is essential for the EU to seize the opportunity to develop data management practices and shape a common ecosystem before these become too widespread; this should be done across all Member States, even if a homogenous approach is not immediately taken. The EU cannot miss the chance to show its leadership in this field and set an example of best practice on data infrastructures, data-driven research and ethical governance. But this leadership cannot be achieved without centralisation and coordination of healthcare policies. 70% of Europeans want the EU to do more in the area of health; Europe needs a Commissioner fully dedicated to health to oversee all the health-related actions across Directorates-General and to address the unique challenges of health data.

By creating equal access to necessary healthcare for its citizens, the EU has already built an exemplary society which other parts of the world look up to. Now, again, it is time for the EU to build a data ecosystem that can stand up as an example to the world, by considering the sensitive data challenges involved in healthcare and by creating healthy societies with fair and effective use of data.

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LETTING EUROPE BREATHE

A Vision for Improving Air Quality in Europe

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ENDORSEMENTS

The Committee would like to thank the following individuals and organisations for the continuous support, guidance, comments, and invaluable suggestions throughout the past six months. This policy brief is a result of collaboration, hard work, and dedication from the team members.

A big thank you to:

- › **Transport & Environment**
- › **European Public Health Alliance** (EPHA)
- › **Clean Air and Environmental Protection Associations** (EFCA)

Petra de Sutter, MD, PhD

*Senator – Parliamentary Assembly Council of Europe
Head of list 2019 European Elections*

"I am very happy to endorse the European Health Parliament's recommendation on air pollution. The air quality directive should urgently be updated in line with WHO guidelines. Environmental issues are not only a matter of health but also of social justice and need to be addressed as a top priority in European policy making."



Biljana Borzan

Member of the European Parliament (S&D, Croatia)

"I commend the Committee on Environment and Human Health for these comprehensive recommendations. The air we breathe, as EU citizens, is so closely connected to so many aspects of our health – from our everyday wellbeing, all the way to preventing longer term conditions related to non-communicable diseases. I congratulate the Committee on tackling this topic by taking into account the different dimensions it encompasses, from city planning to improved cross-policy cooperation. I hope these recommendations mark the beginning of a bigger debate on air quality and human health in Europe."



Pascal Smet

Brussels Minister of Mobility and Public Works

"The airways of our lungs are more important than the highways for our cars. I wholeheartedly subscribe to the recommendations of the European Health Parliament. It's high time our cities and the EU make this a top priority."



EXECUTIVE SUMMARY

The threats to human health posed by air pollution are undeniable, both for current and future generations. Improving the quality of the air we breathe needs to be a priority on the political agenda and it is necessary to deal with it through a holistic approach.

Our recommendations tackle the cross-cutting issue of air pollution, focusing on five pillars:

- 1. The update of the EU Regulatory Framework considering the standards set by the WHO, mainly focusing on the current Ambient and Air Quality Directive.**
- 2. The upgrade of EU monitoring systems and campaigns to raise awareness among citizens.**
- 3. Transport systems and urban planning focusing on reducing pollution from vehicles, tackling both emissions from goods and people transportation.**

- 4. Heating systems, building efficiency and renewable energy. In some countries, pollution due to household heating with solid fuels is one of the main causes of air pollution and can be tackled successfully by investing in renewables and clean technologies.**

- 5. Policies, fiscal systems and incentives aimed at ensuring a coherent approach among EU policies, budgets and national financing schemes.**

Improving air quality is a cross-silo competence in which many issues are at stake. Our policy recommendations aim to involve citizens as well as various stakeholders, from policymakers to doctors, academics and businesses.



INTRODUCTION

Air pollution is the first environmental cause of death in Europe, resulting in more than 400,000 preventable premature deaths per year¹, contributing to a significant proportion of mortality due to chronic obstructive pulmonary disease, lower respiratory illness, ischaemic heart disease, lung cancer, and cerebrovascular disease.^{2,3} As a result, the financial cost of the health effects of air pollution in the region amounts to approximately €1.2 trillion yearly.⁴ Tackling air pollution would not only bring immense health and financial benefits, but it would also contribute to achieving the Sustainable Development Goals (SDGs) while reducing global warming.⁵

Growing scientific evidence and countless climate protests stress the urgency of implementing a sustainable agenda in line with the 2015 Paris Agreement, the Katowice implementing act and the vision for a climate-neutral Europe by 2050.^{6,7,8} On the other hand, social protests like the yellow vests movement triggered by raising fuel tax point to the need to grant specific attention to socially vulnerable groups when taking measures to improve air quality.⁹ Additionally, the recent alarming results of both the European Court of Auditors and the European Environmental Agency suggest that the European region is divided by double standards and demonstrate that the poorer and most vulnerable groups are most affected by air pollution.^{10,11} Hence, reducing social inequalities across Europe and protecting the most vulnerable groups should underpin any efficient environmental and sustainable development policy and vice versa.

The three major causes of outdoor air pollution are (1) burning of fossil fuels, with transport and heating being the most significant, (2) industrial processes and agriculture, and (3) waste treatment.¹² To allow a more focused analysis, these recommendations prioritise mainly transport, heating and policies related to agriculture. We are however aware that this approach has some limitations since it neglects indoor air pollution estimated to cause 4.3 million deaths globally every year, out of which 120,000 are in the European region.¹³

The Committee has developed these recommendations based on comprehensive literature search and feedback from more than 30 experts and policymakers from intergovernmental organisations, EU institutions, national and local authorities, NGOs, the business sector, academia and patient organisations.

"Air pollution is the first environmental cause of death in Europe, resulting in more than 400,000 preventable premature deaths per year."



RECOMMENDATIONS

Review the EU Regulatory framework according to the latest World Health Organisation (WHO) standards

The concentrations of the three most harmful pollutants – particulate matter, nitrogen dioxide and ground-level ozone – are still too high, especially in comparison to the WHO standards. **The current Ambient (Outdoor) and Air Quality Directive fitness check offers an excellent opportunity to adapt the EU standards to the latest recommended by the WHO.**¹⁴

The National Emissions Ceiling Directive (NEC), should set mid-term targets to assure the gradual achievement of 2030 targets.¹⁵ Member States (MS) that are developing their National Air Pollution Control Programmes should, in addition to consulting the public as foreseen by the NEC Directive, also publicly submit a cost-benefit analysis of their programmes featuring a health impact assessment of these plans, which includes health benefits.¹⁶

In order to accelerate compliance, the EU should optimise Members States' accountability and adopt *Implementing Acts* that improve monitoring and clarify the structure of air quality plans (including a timeframe), holding them accountable in a more efficient and timely way when breaching occurs.

In cooperation with the WHO and healthcare professionals, the EU Commission should develop policy proposals, as well as finance guidelines and tools for engagement of other sectors, such as agriculture, transport,



energy and urban planning, and highlight the health and economic benefits that could be achieved by better policy choices. In terms of prevention, citizens should be informed on how to protect their health from air pollution (caused both by traffic and domestic heating). Such guidelines should be widely distributed (schools, hospitals etc.), for example in the form of educational sessions.

Strengthen air quality monitoring to implement targeted policies, raise awareness and guarantee the protection of the most vulnerable groups

Information should be based on an efficient and granular monitoring system critical in providing correct information; it should also hold public authorities accountable (from Member States to cities) and optimise efforts towards improving air quality. To this end, **the current system of EU-authorised monitoring stations needs to be harmonised, improved and enlarged. Additionally, it should be integrated into traffic management systems and information campaigns.**

Clear rules should be established for data transparency, data interpretation, and the number and locations of monitoring stations:

- › Place quality sensors around health facilities, schools and other public places and street canyons (avoiding parks to not distort the real pollution values) that are connected to a warning system^{17,18};
- › Establish new parameters to optimise traffic from the environmental and health perspective (e.g. see Potsdam traffic flow management scheme);
- › **Harmonise cities' air quality warning systems to reduce health inequalities within the EU and avoid double standards.** For example, according to the European Court of Auditors' report, the air considered 'poor' in Brussels is believed 'sufficient' in Krakow¹⁹;
- › **Improve the transparency of apps** and impose them to set conditions on disclosing where information originates from, especially in light of their relation to m-Health;
- › **Educate citizens about the correct usage and interpretation of wearable Personal Exposure Monitoring devices** (that quantify an individual's PM2.5 exposure²⁰) and about the possibility of getting lab-certified results in real time.^{21,22} Citizens should be frequently exposed to air pollution information through billboards in high traffic hubs, comparing the current pollution level to other tangible negatives (e.g. comparing smoked cigarettes as equivalent to the levels of air pollution).

To raise awareness, **the EU should launch an EU campaign/award linked to the Mobility Week (car-free day) and Clean Air Forum** that target national audiences, by putting the spotlight on the actors that work the most toward improving air quality (including cities).^{23,24}

Improve the transport system and implement sustainable and healthy urban planning

Transport accounts for 27% of total EU greenhouse gases (GHG) emissions.²⁵ **Road transport** is estimated to be responsible for 30% of the particulate emissions in European cities – mostly due to diesel traffic.²⁶ Heavy duty vehicles (HDVs), like trucks, buses and coaches, are responsible for 27% of road transport emissions, accounting for ca. 6% of the EU total GHG emissions and it is projected to increase by 56% between 2010 and 2050.²⁷ However, the most carbon-intensive mode of transport is aviation. Between 1995 and 2050, passenger transport in the EU, including aviation, is expected to grow by around 70%.²⁸

"Road transport is estimated to be responsible for 30% of the particulate emissions in European cities – mostly due to diesel traffic." ²⁶

It does not come as a surprise that cities are most affected by air pollution.²⁹ This is why **adopting a holistic approach in transport multimodality and sustainable urban planning is strategic to reduce air pollution.** All stakeholders need to work towards the creation of future-proof cities that implement sustainable transport systems and ease the uptake of sustainable technologies to improve the quality of life and health of their citizens (including the most vulnerable groups).

In light of these considerations, the following recommendations are proposed:

- › **Fix highly polluting vehicles on roads and reform periodic technical inspection.** EU standards should measure pollutants in on-road conditions, ensuring lifetime compliance, and covering harmful pollutants (e.g. ultrafine particles and ammonia). The possibility should be considered of spotting the most polluting vehicles on roads thanks to remote sensing technology linked with automatic number plate recognition.³⁰
- › **Reduce emissions from goods transportation.** While CO₂ emission standards are on the way for new HDVs, **diesel efficiency standards are required for the 'old' circulating HDVs** (98% of lorries are powered on diesel) including hardware upgrades should these vehicles be exported elsewhere.^{31,32} Companies must adopt zero-emission fleets by 2040. Since rail and water transport **(with clean fuel)** are more efficient than road transport, industry should invest in the extension of rail and canal infrastructure in Europe through projects like TEN-T.³³ Investments can be repaid by offering a discount for the use of such infrastructure.
- › **Reduce emissions from personal transportation.** National Air Pollution Control Programmes should include concrete targets related to mobility, like setting a minimum number of electric charging points, car-sharing provisions based on the current number of cars, and access to clean public transport within less than 200 meters in urban areas.
- › **Introduce a "mobility manager" in companies.** This person coordinates employees' commutes and encourages car-sharing also among neighbouring companies.
- › **Increase European cooperation on train transport, including night trains and ensuring fair pricing**

"Funds collected through this taxation scheme must be earmarked to finance clean air initiatives exclusively, such as rail networks and research that accelerates innovation in fuel efficiency of aircrafts and housing."

(EU Mobility Card for the young, elderly and most disadvantaged). The EU Emissions Trading System (EU ETS) should reflect the unfair advantage of aviation over other means of transport in terms of CO₂ emission contribution.³⁴ The amount of **aviation** emissions allowances in circulation set in Directive 2008/101/EC should be auctioned at least 50%, not 15% as it stands.³⁵ Additionally, similarly to the levy on carrier bags to reduce plastic waste, a levy per flight per adult should be introduced on airlines to reduce use of low-cost flights (supported already by the Belgian, Dutch and French governments).^{36,37} **Funds collected through this taxation scheme must be earmarked to finance clean air initiatives exclusively, such as rail networks and research that accelerates innovation in fuel efficiency of aircrafts and housing.**³⁸

- › **Reward citizens and encourage soft/shared mobility schemes.** Many public authorities like the Netherlands or the cities of Bari and Bologna are rewarding their cyclists for keeping themselves active and healthy, while not creating pollution.^{39,40,41} **This strategy could be expanded by rewarding citizens that use public transport or shared mobility schemes:** users' cards and app subscriptions could be linked to their fiscal number to receive tax incentives proportional to the use.
- › **Triple the number of cyclists in Europe by 2025.** To this end, a revision of the EU Regulation 78/2009 regarding the protection of pedestrians and other vulnerable road users should extend its scope to cyclist protection⁴² (by making it compulsory to create separate bike lanes and guaranteeing their trajectory).⁴³ This target can be achieved also by strengthening the Pan-European Master Plan for Cycling Promotion currently under implementation.⁴⁴
- › **Make better use of empty facilities** by allowing residents to park their cars and bikes at night in companies' parking garages, facilitating reallocation of parking spaces for the benefit of bike lanes/pedestrian areas.
- › **Favour land use policies towards city compactness and the reallocation of space by prioritising pedestrians** and ensuring that the existing legislation, such as the Urban Vehicle Access Regulations⁴⁵, is properly implemented considering the benefits this

can bring to human health. Widening, expanding and improving the pedestrian walkways network, including strategies of cooling and shading with green space by **setting a European standard of a minimum square meters of green zones for every citizen** would improve air quality and reduce health inequalities. This includes increasing the green and pedestrian spaces in schools and their surrounding areas, combined with school walking-bus schemes, all of which could lead to fewer cars in use near schools and consequently abate exposure to pollution. In order to focus on protecting health and wellbeing of vulnerable groups and pedestrians in general, a **revision of speed limits in urban areas** should be encouraged (30km/h speed limit instead of 50km/h).⁴⁶

- › **Further encourage national policymakers and other stakeholders to implement best practices in urban planning and sustainable mobility solutions** (walking and cycling infrastructure) via projects like CIVITAS.⁴⁷

Improve heating systems, boost buildings' efficiency and increase uptake of renewables

The heating and cooling of buildings consumes half of the EU's energy and 75% of energy comes from fossil fuels.⁴⁸ Investing in energy efficiency is cheaper than producing renewable energy. The public sector must play a crucial role **by phasing out primary heating from coal and oil fuel by 2030 (or sooner) and upgrading the infrastructure to exploit renewable energy** in regions where phasing out is not yet feasible.⁴⁹ However, it is important to note that 45% of energy in heating and cooling in the EU is used in the residential sector and 36% in industry.⁵⁰ In some European countries, up to three-quarters of outdoor fine particulate matter pollution is due to household solid fuels heating (e.g. coal and biomass).⁵¹

The EHP acknowledges the European Commission strategy adopted in February 2016 as part of the Energy Union Package in order to increase awareness about the health, environmental and long-term financial benefits of investing in energy efficiency.⁵²

- › The **Eco-design Directive** sets minimum requirements for environmental standards of domestic heating products, but Member States remain responsible for **providing incentives to accelerate the uptake of the latest and cleanest technology for renewable energy**.⁵³ Member States should pay particular attention to **vulnerable groups** (for example tenants), who often do not have a say in improving the housing quality

but have to bear the health and financial burden of such deficiencies. If a fast adoption of clean heating is impossible, best practices on the current use of systems like the Clean Heat Project should be encouraged.⁵⁴

- › All businesses (SMEs included) should make the surplus of renewable energy they create available for the market

Adapt policies, fiscal systems and incentives

'Health in all policies' is set by the Lisbon Treaty, the WHO in collaboration with the Finnish Presidency and more recently in the SDGs.^{55,56,57} We recommend a **coherent approach among all EU policies, budgets and national financing schemes**, with a requirement to protect and promote public health.

- › The next European Parliament should strive to secure cleaner air for its citizens, asking DG SANTE to educate policymakers and to request that a systematic air quality-focused health impact assessment is carried out for all relevant policies. Different taxation mechanisms should be compared in terms of their cost-effectiveness to deliver on health benefits. The environmental impact of fossil fuels should be considered in countries' taxation policies to avoid under-taxing diesel in comparison to gasoline, and the **EU rules on energy taxation should be revised accordingly**. Similarly, EU schemes such as **Cohesion funds, EFSI, Horizon Europe, the EU Urban Agenda, and funding from the European Investment Bank** should be instruments to achieve the objectives of the air quality legislation (e.g. by encouraging the creation of **geothermal implants/district heating in cities**).
- › With 37% of the EU budget allocated to the Common Agricultural Policy (CAP),⁵⁸ EU citizens expect the CAP to make a stronger contribution to the environment. The agricultural sector accounts for 10% of the EU's total greenhouse gas (GHG) emissions.⁵⁹ Agricultural emissions

of ammonia and methane continue to exceed air quality thresholds.⁶⁰ The proposed CAP Strategic Plan beyond 2020 must **set EU-specific GHG targets on ammonia and methane emission reductions** that translate into an ambitious conditionality and associated **subsidies ring-fenced on air quality improvement**.

- › Monitoring and evaluation of performance should use indicators that would not be offset by emissions from other parts of the world.⁶¹ With nearly 72% of CAP fund income support for farmers⁶², GHG reduction beyond targets can be further **incentivised with attractive top-up payments** on additional clean air-specific interventions implemented under voluntary Eco-schemes (Pillar I) and Environment Management Commitment (Pillar II). Overall, the public sector must set an example and accelerate progress towards better public health through better air quality. To this end, sustainable and strategic public procurement criteria in the tendering process should be mandatory to create market demand and speed up suppliers' capability to innovate and deliver more on sustainably.⁶³
- › Similar to the Framework Convention on Tobacco Control, the EC should actively engage those who work in health and other relevant policies in tackling air pollution by stepping up on the global stage and **calling for a binding instrument on Air Quality**.

"We recommend a coherent approach among all EU policies, budgets and national financing schemes, with a requirement to protect and promote public health."



CONCLUSIONS

th Committee on
ental & Human

- Arianna Gamba

SPEAKERS

- François Wakenhut, Head of Unit for Clean Air, DG Environment, European Commission
- Yoann Le Petit, Clean Vehicles & New Mobility Officer, Transport & Environment
- Susanna Palkonen, Director, European Federation of Allergy and Airways Disease Associations

#WERUN4HEALTH

Air pollution remains a global pandemic, with low-income individuals suffering the highest risk of the associated consequences in terms of health. The Committee has developed recommendations focusing on regulatory policies, transportation and urban planning, heating and renewables, and economic incentives.

Air pollution is by definition a pan-European, cross-border issue: an improvement of air quality in one city or country is often neutralised by an industrial zone outside of the city or across the border. Best practices that inspired these recommendations have proven that it is possible to improve air quality and reduce the related mortality and morbidity rates via implementation of the European regulatory framework. Hence, the determinant factors to make all of the puzzle pieces fit together and bring positive results at all levels are political will, as well as a collaborative cross-sector approach integrating the health, social and environmental outcomes of any activity. It is time to act in order to let Europe breathe again.

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LEADING HEALTH INNOVATION TOWARDS VALUE IN EUROPE

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ENDORSEMENTS

The Committee would like to thank the following individuals and organisations for the continuous support, guidance, comments, and invaluable suggestions throughout the past six months. This policy brief is a result of collaboration, hard work, and dedication from the team members.

A big thank you to:

- › **European Health Management Association (EHMA)**
- › **European Cancer Patient Coalition (ECPC)**

José Inácio Faria

Member of the European Parliament (EPP, Portugal)



"Innovation in healthcare is only true when it undoubtedly responds to both the needs of individuals and of health systems as a whole. I believe that a wider concept of innovation is flourishing in these recommendations of the Health Parliament. The value of innovation needs to encompass patients' quality of life, accessibility to and affordability of healthcare systems, as well as to cover the preparation of the societal network where it will land. Innovative technologies for prevention, diagnosis and treatment are only beneficial when all know how to put them to good use."

Prof. Walter Ricciardi

Professor of Hygiene and Public Health at the Università Cattolica del Sacro Cuore, Member of the Executive Board of the WHO, Member of the Expert Panel on Effective Ways of Investing in Health (European Commission, DG SANTE)



"I congratulate this Committee of EHP4 for addressing the difficult but pressing topic of steering innovation towards value to preserve the sustainability of our health systems. Health systems are increasingly faced with multiple socio-economic challenges. All these processes must be governed, or the result will be more differences across and between countries and additional shocks to our healthcare systems. Proposals such as the European Health Innovation Day and preparing health workforce to share and deliver innovations within healthcare systems are pivotal to promote a common understanding of value in our healthcare systems. The challenges and solutions identified in this brief provide critical insights for decision-making, which inevitably needs to be made by political and health system managers."

EXECUTIVE SUMMARY

European Member States are increasingly faced with multiple socio-economic issues that challenge the sustainability of their healthcare systems. Aware of such challenges, young Europeans are eager to harness and protect the potential of health innovation, which could bring sustainable solutions to some of today's most pressing issues.

Health innovation should bring added value to people's health and wellbeing through increased efficiency, effectiveness, safety, quality, affordability and sustainability. It can take multiple forms, such as breakthrough treatments, novel technologies and improved processes and services that empower citizens and patients.

We want the European Union to be a global leader in the development and implementation of health innovation. We want Europe to be conducive to innovation and to place patients and citizens at the centre when shaping the future of health – if not for the seven in ten Europeans who believe that the EU should do more in terms of health, then for future generations.

To stimulate health innovation and its value for the next generations, we recommend to:

1. Set up a "European Health Innovation Day" to promote a common understanding on the value of health innovation and engage European citizens in setting health priorities.
2. Develop an EU framework for patient involvement in the full life-cycle of health innovation development.
3. Facilitate the objective assessment of all factors important to patients and caregivers in healthcare resource decisions.
4. Establish a permanent EU body to prepare for the regulatory and ethical challenges of disruptive technologies.
5. Prepare the health workforce to deliver innovation within health systems.
6. Broaden and facilitate the appraisal and decision-making on health innovations within the European market to benefit decision makers, patients and innovators.



INTRODUCTION

European healthcare systems are increasingly faced with multiple socio-economic challenges, including a rise in non-communicable diseases, multimorbidity, antibiotic resistance, healthcare costs and funding deficiencies, and an ageing population.¹ Within this context, health systems and policies struggle to anticipate, manage and understand the implications of innovation.

Aware of such challenges, young Europeans also recognise the potential of innovation in providing sustainable solutions to preserve our healthcare systems. Health innovation can and indeed should bring added value to people's health and wellbeing through increased efficiency, effectiveness, quality, sustainability, safety and affordability.² It can take the form of breakthrough treatments and novel technologies, but can also entail new or improved processes and services that change the way in which healthcare is delivered and empowers citizens.³ Innovation is not just about technology, it also encompasses cultural, organisational and conceptual aspects in the way our health systems are designed. Regulation should not hamper innovation in the health sector but should support and push for it to be valuable both to patients and society at large.

In its effort to support Member States' healthcare systems, the European Union (EU) can play an important role in enabling the scaling of benefits for producers and the alignment of priorities between Member States. We want the EU to be a global leader in the development and implementation of health innovations. We want Europe to be conducive to innovation and to place patients and citizens at the centre of shaping the future of health. This policy brief therefore provides six recommendations on how the EU and Member States may generate novel policies which would foster valuable health innovation and place patients and society at the centre of the healthcare innovation ecosystem.

"Innovation is not just about technology, it also encompasses cultural, organisational and conceptual aspects in the way our health systems are designed."



OUR APPROACH



For the development of this policy brief, members of the Committee on Innovation and Value conducted 22 interviews with experts and representatives from across the entire healthcare ecosystem, including industry (7), patients (4), policymakers (8) and academia (3). The outcomes of these interviews were supplemented with desk research focusing on setting priorities for innovation, assessing innovations and the patient access pathway, as well as ensuring the swift and safe implementation of innovations. All the research was horizontally informed by the ambition to better serve European patients and citizens.

The authors of this report decided to focus on key ideas rather than on the political implications of the recommendations. As such, the policy recommendations are aimed at the EU as a whole, including its institutions and its Member States. As it tackles only some of the many issues encountered when bringing valuable innovations to patients, we strongly encourage the next European Parliament and Commission to continue exploring how they can contribute to an innovative and healthy future for Europe.

RECOMMENDATIONS

Set up a “European Health Innovation Day” to promote a common understanding on the value of health innovation and engage European citizens in setting health priorities

Even if innovation has significantly contributed to a rising life expectancy⁴, citizens do not necessarily fully understand the associated socio-economic benefits. The EU should proclaim a **“European Health Innovation Day” as a platform for dialogue** between citizens and governments to establish **a common understanding of health innovation, of its societal cost, and also of the role and value it brings to European society.** This would help citizens to elect representatives that champion their views on the future of health, and further support governments in making complex trade-offs when allocating budgets on treatments, health systems, disease prevention and research into unmet medical needs.

During the European Health Innovation Day, the EU should support Member States to:

- › Launch **national public surveys on health priorities** tailored to regional contexts;
- › Conduct **educational programmes in schools**, for instance by bringing students to hospitals, laboratories or innovative companies, educating them on the latest technologies, and promoting career paths to actively shape the future of our innovation and healthcare systems;
- › **Break the silos in the decision-making processes** which define health investment by fostering a dialogue between health, finance, social and environmental decision makers;
- › Extensively **leverage new social media** and other means to gain wide visibility and continuous engagement.



"Break the silos in the decision-making processes which define health investment by fostering a dialogue between health, finance, social and environmental decision makers."

Develop an EU framework on patient involvement in the full life-cycle of health innovation development

Existing codes of practice for patient involvement do not comprehensively cover the life-cycle of innovation. Indeed, meaningful patient involvement across all phases can bring multiple benefits to researchers, patients, clinicians and society.⁵ The EU should build on the work of the ongoing PARADIGM and EUPATI projects to develop **a clear framework for patient involvement in health innovation and ensure an EU-wide, sector-wide, comprehensive uptake.**

The framework for patient involvement in health innovation should:

- › Cover all health innovations and enable meaningful patient engagement **in the entire life-cycle of**

innovation, from setting research priorities and participating in research design, to research operations and dissemination;

- › Facilitate **a continued and transparent interaction** between the pharmaceutical industry and patients, following clear regulation put in place to this end;
- › Include **clear standards on how to frame and accurately report** the results of meaningful patient involvement.

Trade and research associations should play an important role in the wide roll-out of the framework through its inclusion into their internal regulations (e.g. EFPIA Code of Practice on Relationships between the Pharmaceutical Industry and Patient Organisations⁶).

Facilitate the objective assessment of all factors important to patients and caregivers in healthcare resource decisions

Health innovation is often solely viewed as the development of ground-breaking new curative treatments. However, there is also great societal value in **innovations that incrementally improve the everyday lives of patients and their caregivers**.⁷ This could be the new formulation of an existing molecule which may reduce the intake frequency or mitigate side effects⁸, or a mobile app which can answer medical questions on demand.⁹

To adequately assess the value of such innovations, and to incentivise innovators to consider both clinical and non-clinical outcomes of their products, thereby reflecting more patient value, the EU should:

- › Further **facilitate research in advancing meaningful quality of life outcome measures**¹⁰, especially patient and caregiver reported treatment outcome measures (PROMs & CROMs), and patient reported experience measures (PREMs);
- › **Boost research on factors important to patients and their caregivers** and how to measure them¹¹;
- › Facilitate the **adoption of value assessment frameworks** at national level. This would open doors to capture and measure factors relevant for patients in a more accountable, objective and transparent way across the EU.

Establish an EU permanent body to prepare for regulatory and ethical challenges of disruptive technologies

Innovations in healthcare are often held back by lack of regulatory guidance or framework.¹² At the same time, patients and citizens increasingly seek access to new technologies independently of whether these are regulated or not.¹³ This can be exacerbated by the speed at which especially digital innovation continues to rise. Soon enough, citizens could be able to 3D print their own biomaterials and medicines, rely on artificial intelligence instead of doctors, or even ensure their "digital immortality".¹⁴

The EU should establish a permanent body specialising in long-term disruptive health innovation horizon scanning.

This body could be a standalone EU agency, a new unit within the European Commission or a committee of the European Medicines Agency. By dealing with digital and disruptive care with a long-term perspective, the EU can support Member States in preparing their healthcare systems, regulatory frameworks and access pathways, prompting global EU leadership in the field of health innovation. This permanent EU-level body – that we call the Health Innovation Centre – should:

- › **Analyse novel and anticipated technologies** and issue guidance on their potential impact from technological, health systems, ethical, political and economic angles.
- › **Ensure the system readiness for innovations** by working closely with the Member States and key stakeholders, through e.g. the eHealth Network and the European Commission's eHealth Stakeholder Group¹⁵, whilst ensuring **the right level of citizen protection**.
- › Operate as **an embedded body within an existing EU institution** to inform the work of adjacent policy units and ensure horizontal integration of emerging future health solutions in all policies. It should further identify knowledge gaps and pilot opportunities for research programmes.

"By dealing with digital and disruptive care with a long-term perspective, the EU can support Member States in preparing their healthcare systems, regulatory frameworks and access pathways, prompting global EU leadership in the field of health innovation."

Prepare the health workforce to deliver innovation within health systems

Although the number of physicians and nurses in Europe has increased by approximately 10% over the last ten years¹⁶, there are still worrying shortages of health professionals and this gap is set to rise as the health needs of our societies continue to grow.¹⁷ Under these strains, an additional effort is needed to **ensure that our health workforce is trained and fully equipped to bring innovations to patients.**

At the same time, innovation could **contribute to relieving health workforce imbalances** as it boosts efficiency of care.¹⁸ For example, the deployment of AI could help doctors review mammograms 30 times faster and 99% more accurately than before, which would lead to much earlier detection of breast cancer.¹⁹

To harness such potential from innovation in practice, we call on the EU to:

- › Provide **guidance for medical education facilities** on how to best prepare future health professionals to **disruptive innovation** in their practice;
- › Co-create **interactive e-learning tools** with and for health workers on the use and adoption of new technologies in healthcare. This way, health professionals can become **champions for change in health and care delivery** and impact the uptake of new technologies in healthcare systems²⁰;
- › Increase the number of **cross-country educational and training projects** accessible to all professionals of health and care delivery;
- › Identify and spread **local best practices and key learning experiences** of health workforce training, with view to incorporating innovations into daily use. To this end, the EU should incentivise individuals and institutions to use a centralised platform where health providers and institutions can access and submit case-based reports of real-life best practices and key learning experiences.

Broaden and facilitate the appraisal and decision making on health innovations within the European market to benefit decision makers, patients and innovators.

Health Technology Assessment (HTA) plays a vital role in getting innovations into reimbursed healthcare and to patients.²¹ So far, it is mainly used for new medicines across EU Member States²², with only 58% of national HTA institutions assessing technologies such as IT, e-health and m-health technologies, population level interventions and service delivery systems.²³ To be ready for the next generation of health innovations, the EU should set **ambitious goals to achieve common HTA frameworks for health innovations**, including specific medical devices, services and processes. The EU should support Member States to:

- › Perform **HTA on health innovations**, including technologies and processes to ensure that health resource allocation decisions are value-based;
- › Establish a **single point of contact** responsible for **defining clear patient-access pathways** for all innovations in healthcare, making sure that the process is both transparent for citizens and clear for companies;
- › Build on the European Commission proposal for a joint-EU HTA to **further harmonise HTA processes and methodologies** throughout the EU.

While we fully acknowledge that convergence and centralisation of HTA systems remains a contentious and controversial political topic, we believe it is important to further suggest that the EU and Member states should **gradually work towards coordination and possibly centralisation of HTA expertise on relative clinical benefits**. Scaling benefits and pooling expertise in the HTA process will be a key element in addressing the resource challenges that come with evaluating a whole new class of health innovations.



CONCLUSIONS



The main aim of our policy brief has been to present various suggestions on how the EU can be a proactive agent which enables valuable and innovative change in European healthcare systems. Indeed, as we have discussed, there are still strides to be made in order to develop novel sustainable policies capable of fostering valuable health innovation and placing patients and society at the centre of healthcare systems. This is why we firmly believe that the EU is, more than ever, needed to support regulatory systems, healthcare workforce, and most of all citizens to make the most out of current and future opportunities.

However, with health innovation having such powerful potential, the difficulty lies in defining and prioritising the exact roles, out of many, that the EU can play to facilitate such processes. Moving beyond the EU's community acquis, notably the many benefits reaped from the Single Market in enabling innovation across EU countries, our aim has been to demonstrate that the EU has the potential and the capacity to be the key actor that guides innovation in the direction of where it should be most valuable.

Innovation is, by nature, unpredictable and the speed with which it is taking over our daily lives is nearly surpassing our ability to harness it. Let's once and for all embrace this unique opportunity by empowering the EU and its Member States to make positive disruption and valuable innovation the cornerstone of European healthcare.

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A SPECIAL THANKS TO

EHP PARTNERS

Johnson & Johnson

Luca Bellomo

Kunegonde Carpentier

Zeger Vercouteren

Leonie Volker

POLITICO

Laura Bartz

Beth Chamberlain

European Patients' Forum

Valentina Strammiello

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NOTES

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