

# **EUROPEAN HEALTH PARLIAMENT**

**EUROPE'S NEXT GENERATION OF HEALTH**

## **Recommendations by the Next Generation**

**2019-2020**

**#EUHealthGen**



**Think Digital**



**Think Patient**



**Think Global**



# Table of Contents

## Forewords

|                                 |           |
|---------------------------------|-----------|
| <b>Zeger Vercooteren</b> .....  | <b>7</b>  |
| <b>Katie Gallagher</b> .....    | <b>8</b>  |
| <b>Olivier Costa</b> .....      | <b>9</b>  |
| <b>Gardenia Trezzini</b> .....  | <b>10</b> |
| <b>Jason Descamps</b> .....     | <b>10</b> |
| <b>Alessandro Da Rold</b> ..... | <b>11</b> |
| <b>Thomas Gelin</b> .....       | <b>12</b> |
| <b>Bjelle Roberts</b> .....     | <b>13</b> |

## Recommendations

|   |           |
|---|-----------|
| <b>Interconnected Care</b> .....  | <b>16</b> |
| The Future Is Cross-Border: Ensuring the Portability and Accessibility of Personal Health Records within the European Union |           |
| <b>Europe as a Health Innovation Hub</b> .....  | <b>30</b> |
| Europe: a Leader and World-Class R&D Innovation Hub for the Benefit of Patients, Healthcare Systems and the Economy         |           |
| <b>Sustainable and Healthy Lifestyles</b> .....   | <b>44</b> |
| Paving the Way for Europe's Next Generation of Health   |           |
| <b>Tackling Cancer in Europe</b> .....  | <b>56</b> |
| Remaining One Step Ahead to Beat Cancer   |           |
| <b>Mental Health and Healthy Workforce</b> .....  | <b>70</b> |
| Towards a Healthy Workforce in the EU – Implementing Actions for Sustainable Work Life                                      |           |



# THE NEXT GENERATION OF EU HEALTH LEADERS

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, European Patients' Forum, EU40, College of Europe, Porter Novelli, Euronews and Mavence 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.



EUROPEAN  
HEALTH PARLIAMENT

EUROPE'S BEST REPRESENTATION OF HEALTH

HealthGen

2019-2020

# FOREWORDS



Health Parliament



Preventing, diagnosing  
and treating  
cardiovascular  
diseases in Europe

# ZEGER VERCOUTEREN

Worldwide Government Affairs and Policy Vice President,  
Europe, Middle East & Africa and Global Supply Chain

Johnson & Johnson



This is a special moment in the history of the European Health Parliament. The start of a new European policy cycle, combined with the need to adapt and improve following the COVID-19 crisis, has made this a unique opportunity for renewal and innovation. This edition has been a year of firsts: the EHP's first-ever health hackathon, introducing a dynamic and innovative working style to the program; and the EHP's first-ever all digital plenary session, introducing a greener, fresher and equally engaging platform for bringing together a diverse range of stakeholders. As we look to the future of European health in a period of renewal, please join us in re-writing the rule book and welcoming a few more firsts that could help improve people's lives.

In 2020, Europe is reacting to a public health crisis that has challenged and stretched health systems across the continent. Alongside the response to the pandemic, health systems are facing ongoing pressures to adapt their spending and other resources to match ever-changing demographics, rising disease burdens, stronger patient empowerment and modern technologies. The task for all those working in health is to look to the future to carve a path to recover and to build ever more resilient, innovative and efficient healthcare systems.

This 5th edition of the EHP is exactly that – a look to the future of European health envisaged by the next generation of future health leaders. In this edition, the EHP members were tasked with situating their recommendations within the frame of three cross-cutting themes:

- › **Think Patient**
- › **Think Digital**
- › **Think Global**

In the midst of the COVID-19 global health crisis, we cannot help but be reminded of the importance of these themes. COVID-19 is a global problem, reminding us that, in an ever more interconnected world, our health solutions must be global too; amongst this, we have all adapted and adopted digital solutions which have helped us remain connected

indicating that the future of healthcare can also be increasingly digital. In addition, these difficult times have served as an important reminder of our primary responsibility, to protect the lives and improve the well-being of European patients and citizens.

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 on five major policy topics (Mental Health and Healthy Workforces; Tackling Cancer in Europe; Europe as a Health Innovation Hub; Interconnected care; and Sustainable and Healthy Lifestyles) are innovative, actionable and to the point. This makes their work so valuable to the EU institutions and its policymakers as demonstrated by the great interest, engagement and support of many EU policy makers and stakeholders.

Not only do the EHP members set out in this document their recommendations for how to carve this path in five key topic areas, many of the EHP's young healthcare leaders will undoubtedly play a role in bringing this future into fruition in the years to come. The EHP helps students and young professionals from very diverse backgrounds and nationalities to connect genuinely with the European project. The 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 – the rest is up to them!

Johnson & Johnson, in collaboration with the other EHP partners, truly prides itself on preparing and empowering EU young professionals to advocate for what matters most to their generation. On behalf of Johnson & Johnson, I would like to wish the EHP members the very best of luck in all their future endeavours and look forward to staying closely in touch and following their growing careers with real interest.

Follow the buzz generated on social media by this young and knowledgeable crowd – let's all join this year: #EUHealthGen to follow all our updates and #EHPGoesDigital to follow our virtual meetings.

# KATIE GALLAGHER

Senior Policy Adviser

European Patients' Forum (EPF)



2020 is proving to be without any doubt one of the most challenging years for healthcare in the human history. The COVID-19 pandemic had and it still having a radical impact on the lives of almost every single person in the world and it fundamentally shook our health systems.

If from one side the crisis has exacerbated existing issues such as access to care, medicine shortages and health inequalities, on the other side it had also exposed new gaps and challenges, showing us once again the complexity of healthcare.

However, great challenges can also push for positive changes and innovation. COVID-19, for example, has demonstrated again how innovation in healthcare, both digital and organisational, if designed and implemented in the right way, is fundamental to support and improve care delivery and quality.

That is why, the EHP and its focus on fresh and innovative solutions to common health challenges, proved once again to be an incredibly positive initiative. With healthcare being more and more at the forefront of the European debate, it is of outmost importance to come together to discuss the future of health and care.

For EPF, it has been a pleasure to have been partners of the 5th edition of the EHP. The contribution of so many talented young passionate professionals who have worked hard in tackling the most pressing issues for health in Europe was impressive and timely. It was great to see this strong team of motivated and knowledgeable individuals address these issues with expertise and competence and develop concrete, evidence-based recommendations. I was also happy to note that this year's EHP included crucial elements from patient perspective, giving great importance, for example, to empowerment and inclusiveness, health literacy, mental health, better interaction with healthcare professionals, and healthy lifestyles.

For EPF, these are all fundamental: nobody will help us drive positive change and person-centred innovation in health systems beyond COVID-19 better than patients themselves. They have invaluable experiential knowledge and expertise through living with a disease and they must be supported and included in shaping and navigating health system, picking up what really works and where there are gaps and weaknesses.

In conclusion, I would also like to applaud all the committees for engaging with and securing endorsements by an impressive wide range of important stakeholders, including key Members of the European Parliament, European Commission officials, patients and civil society representatives, national and regional experts. This is excellent news, and it adds even more credibility and recognition, even beyond the EU Brussels bubble to the brilliant recommendations put forward by the EHPers.

**Health is changing at global level and initiative as the EHP, with its energy and fresh ideas can support policy makers in shaping the future of health in the EU, strengthening our health systems and making them more resilient to current and future challenges. My warmest congratulations to everyone at the European Health Parliament!**

## OLIVIER COSTA

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



Last year, I started my foreword by noting that the importance of public health for European societies was undervalued because of the focus of policy-makers, the media and citizens on other topics, such as the refugee crisis, the state of international relations, or climate change.

### **With the COVID-19 crisis, things have changed in an unexpected and radical way.**

This crisis has demonstrated that public health structures and social protection systems are fragile. It has shown how deeply a pandemic can impact the economy. In the last few months, EU actors have been constrained to brainstorm on the issue, to propose new initiative and to set up an historic recovery plan.

More than ever, there is 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, Euronews, EPF, EU40, Mavence, 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 Fifth EHP will inspire once again EU policy makers, especially in view of the post-COVID context.



## **GARDENIA TREZZINI**

**Chief of Brussels Bureau  
Euronews**

As the number one international news channel in Europe, Euronews cultivates and promotes a pan-European perspective where all views and voices are welcome. Our mission is to empower people across the continent – and beyond – to form their own opinion.

**In a similar vein, the European Health Parliament brings together a variety of participants who, through a collective effort of debate and reflection, propose solutions to public health challenges.**

In the unprecedented year of 2020, our role as media partner called for a great deal of creativity and flexibility. Despite the multiple challenges posed by the ongoing pandemic, we are proud of our collaboration with the EHP to adapt the initiative to the new normal: digital, socially distant, safe and responsible, but also dynamic, innovative and inclusive.

Euronews has allowed the EHP to access audiences in 12 different languages. As of today, Euronews is available in almost 400 million homes across 160 countries, including 67% of homes in the EU and the UK, reaching 150 million people every month.



## **JASON DESCAMPS**

**Founder and Director  
Mavence**

Mavence, formerly EARS – European Affairs Recruitment Specialists, has been the recruitment partner of the EHP since 2017 and became this year one of the few official Partners of this initiative.

This year's edition has been challenged by the covid-19 global pandemic, but from the kick-off meeting in Brussels through to completion of this edition I was impressed by the level of commitment and dedication from the participants, coming from all over Europe. The Millennial generation the participants belong to is known for having new sets of expectations, but they also backed them up with ideas, suggestions and even challenged the status quo in many areas.

Observing the dynamics in the various topical groups, I have noticed leadership, great team working spirit and adaptability in overcoming differences at various levels.

**It is uncontested that the EHP is THE platform to advance the healthcare policy debate in Europe and to connect with all the relevant stakeholders on an equal footing.**

# ALESSANDRO DA ROLD

Managing Director  
EU40



The latest months have been one of the most challenging times of the last 100 years. The importance of living healthy lifestyles, of taking care of our health and making sure we protect the people around us has entered more than ever in our daily lives. We had to face many obstacles and find creative solutions during this crisis, and the sudden lockdown has truly shown that together we can make a real difference, creating meaningful change and bettering our future. Now, more than ever, we experience the need of people coming together, and the European Health Parliament represents, as always, a great occasion to do so.

**The EHP has the incredible value of bringing together young professionals in a variety of fields and creating safe spaces where they can connect with EU politicians, policymakers, associations and the industry.**

This networking exercise allows all participants to get a 360 degrees experience on how the world of policymaking works, and teach them valuable lessons for their future respective jobs. On the other hand, this initiative brings new and fresh ideas in the political panorama, and those ideas are even more powerful, as they come from young professionals who experience on a daily basis both the positive and negative sides of the current European health sector. Tackling cancer, protecting our mental health,

bringing innovation, digital and interconnected healthcare and adopting more healthy lifestyles are all top priorities for our EU citizens, and the following recommendations I believe are a fantastic starting point for policymakers to make sure they take into consideration the experiences and hopes of the young professionals that work in the field.

The EHP created a win-win situation for the health sector and the EU policymakers, and it is a pleasure and an honour for EU40 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 of supporting so many good ideas that have the genuine potential to make Europe the world's healthiest continent.

# THOMAS GELIN

Senior Vice President, Europe Policy Lead, Health  
Porter Novelli



The COVID-19 pandemic has exposed a foundational weakness in our healthcare systems. Without investment in key areas such as primary care; outpatient technology; data-sharing; and a move to prospective payment and value-based care models – we will be no more prepared for the next public health crisis than we were for this one.

Europe's recent commitment to set up a new policy framework (e.g. EU4Health, New Pharmaceutical Strategy, Europe's Beating Cancer Plan) is going in the right direction. These initiatives can undoubtedly help reshape our healthcare delivery system, from reactive to proactive, from hospital-centred to community-centred and ultimately from a focus on sickness to life-long wellbeing. But we desperately need to go beyond our traditional policy approach to truly drive sustainable and inclusive innovation in health...

**EHP: a force for change in Europe!**

Because EHP embraces the aspirations of the young generation in unique ways, it has gained incredible support among key EU and national decision-makers and stakeholders seeking for innovative, multidisciplinary solutions in health.

**This year again, the next generation of health leaders has worked relentlessly to develop a set of disruptive, actionable ideas to improve health in Europe. I am very pleased to support this dynamic community of young talents who has set new standards in digital, forward-thinking advocacy in Europe.**

Their policy recommendations related to cancer policy, innovation in Europe, mental health, interconnected care, and healthy lifestyles will undoubtedly enrich policy discussions and help design sustainable healthcare solutions for a post COVID Europe.

# BJELLE ROBERTS

EHP5 President



The year 2020 has been an extraordinary year for the entire globe. The ongoing COVID-19 pandemic has led to disruptions, challenges, and changes beyond expectations. It brought to light the weaknesses in our healthcare systems and the inequalities within and between countries. Above all, it underlines our political differences and the importance of solidarity in a globalised world.

The entire essence of the European Union has been called upon during this pandemic – including its values such as human rights, equality, freedom and democracy. Now, more than ever, it is essential we work together to rebuild a better future for EU citizens with health at its basis ensuring protection of the population and striving for economic prosperity.

Health has been put at the top of the agenda at EU and national level, supported by a significant EU recovery plan for the 'Next Generation EU' (NGEU). This investment will support not only health, but also green- and digital transitions. These themes are significantly interconnected and should serve as key pillars in creating a sustainable and resilient Europe of the future.

Over 2020, the European Health Parliament, representing 60 young leaders in the field of health spread across Europe, has been dedicated to creating recommendations identifying and informing on the most pressing issues in health today – including those mentioned above.

With great pride, I would like to introduce the phenomenal work done by the 5 committees, namely:

- › **Tackling Cancer in Europe**
- › **Europe as a health innovation hub**
- › **Interconnected care**
- › **Sustainable and healthy lifestyles**
- › **Mental health and healthy workforce**

In the upcoming pages, pressing topics with actionable recommendations are presented. The vision of the youth brought forward through these recommendations offers new concepts on how we need to move from healthcare systems to health systems, how digital transformation and innovation is of tremendous value, and how citizens should be at the centre of health policy.

**The future of Europe begins now.**





# RECOMMENDATIONS

# COMMITTEE FOR INTERCONNECTED CARE



## The Future Is Cross-Border: Ensuring the Portability and Accessibility of Personal Health Records within the European Union

Chair

**Tatiana Dias**

Vice Chair

**Jana Backers**

Members

**Bjelle Roberts**

**Borislava Ananieva**

**César Gutiérrez Fernández**

**Emil Tan**

**Evelina Kozubovska**

**Fausto Comandè**

**Louis Bertin**

**Maria Teresa Costa Pereira de Oliveira**

**Maria Tinoco**

**Marina Makri**

# ACKNOWLEDGEMENTS

The Interconnected Care Committee would like to thank the following individuals/organisations for the contribution to the work of the Committee during the past months. The final policy recommendations are a result of essential feedback and discussion between the committee members and experts in interconnected care and e-health digital transformation. Their contribution does not necessarily imply endorsement of the specific policy recommendations.

- › **Eliana Barrenho**, Organisation for Economic Co-operation and Development
- › **Mariano Votta**, Active Citizenship Network
- › **Paul De Raeve**, European Federation of Nurses Associations
- › **Paul Timmers**, EIT Health
- › **Dr. Petra Wilson**, FTI Consulting
- › **Saira Arif**, ORCHA – The Organisation for the Review of Care and Health Applications
- › **Tiago Oliveira**, Organisation for Economic Co-operation and Development
- › **DG SANTE**, Unit B3 – European Reference Networks and Digital Health

# ENDORSEMENTS

- › **Adnan El Bakri**, MD & CEO Founder, InnovHealth
- › **Tomislav Sokol**, Member of the European Parliament (EPP, Croatia)
- › **Katalin Cseh**, Member of the European Parliament (Renew Europe, Hungary)
- › **EFN**, European Federation of Nurses Associations
- › **ACN**, Active Citizenship Network
- › **EUREGHA**, European Regional and Local Health Authorities
- › **Kristine Sørensen**, PhD, Founder, Global Health Literacy Academy
- › **ECHAlliance**, European Connected Health Alliance



**Tiemo Wölken**  
Member of the European  
Parliament (S&D, Germany)

“I am very happy to endorse the European Health Parliament’s recommendation on enhancing European coordination and competence on health. The policy recommendations from the Interconnected Care Committee are thorough and very comprehensive. Only with a strong and close coordination the EU will be able to overcome current and future crisis. The focus on interoperability and intensified exchange of health data will be key for future cooperation within the Union for the benefit of our patients, especially when it comes to rare diseases. The improvement of health data sharing infrastructure will, therefore, be key. Moreover, there is a clear need for better cross-border cooperation that involves all stakeholders including patient and patient organisations. Every person, without any discrimination, has the right to equal and affordable access to modern and comprehensive healthcare. It is high time we make health one of the top priorities in European policy.”



**Lars Münter**

Head of International Projects  
Unit, Danish Committee for  
Health Education

“The work and recommendations of the Interconnected Care Committee of the European Health Parliament are vital for our future, as we also need to build attention to detail and an eye for the bigger picture; Without investments in health and wellbeing, the road towards sustainable societies becomes blocked. Without tackling and engaging communities in solving health determinants and health literacy, our wheels will be forever stuck. A future economy of wellbeing – and policies to support it – are the path and goal for progress. Never has health in all policies made more sense.”



**Adalberto Campos Fernandes**

Professor of National School  
of Public Health, NOVA  
University of Lisbon

“The pandemic crisis associated with COVID-19 amply demonstrated the strategic importance, in public health, of technologies and information systems. Currently, it is essential to ensure the integration of the different systems, to deepen multisectoral cooperation and to strengthen international collaboration. The success of this strategy depends on citizens’ empowerment, healthcare professionals’ digital literacy and health data-sharing infrastructure. The report of the Committee on Interconnected Care: The Future Is Cross-Border – Ensuring the Portability and Accessibility of Personal Health Records within the EU represents a decisive contribution to the production of the essential strategic thinking in the European context. Modern information technologies will allow, in the future, a greater focus on health policy adequately meeting citizens’ health needs. This insightful report provides innovative ideas regarding the importance of the digital transition and its transformative impact on health systems and the active role of citizens in managing their health pathways.”

# EXECUTIVE SUMMARY

The current coronavirus (COVID-19) outbreak has showcased the need for better connected healthcare systems and a more coordinated approach in cross-border health policies in the European Union (EU). Ever-increasing mobility requires greater legal certainty on citizens' rights when it comes to access to healthcare abroad, as well as suitable and efficient infrastructures to enable such rights to be respected and upheld. Notwithstanding the landmark adoption of Directive 2011/24/EU on Patients' Rights in Cross-Border Healthcare, persisting shortcomings in deploying EU-wide eHealth infrastructures and the limited impact of such legislation on citizens' life point at the distance between the statements of principle and their full implementation on the ground.

In this context, the Committee for Interconnected Care would like to draw EU policymakers' attention towards the issue of insufficient interoperability, portability and accessibility of personal health records across borders. Our recommendations are focused on three pillars:

- 1. Citizens' education and empowerment**
- 2. Healthcare professionals' trust and literacy in digital technologies**
- 3. Health data sharing infrastructure**



# INTRODUCTION

An increasing number of people crossing European borders has resulted in a growing need to access healthcare in a foreign country.<sup>1-3</sup> Article 168 of the Treaty on the Functioning of the European Union specifies that “a high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities”, thereby mainstreaming health-related priorities across all actions developed at European level, and in the way that Member States implement European Union (EU) law ‘at home’. Directive 2011/24/EU<sup>4</sup> on patients’ rights in cross-border healthcare was put in place with the aim of facilitating such access across the EU.<sup>5</sup>

Access to interoperable digital health records in any EU Member State is key to enabling innovative, connected and integrated cross-border health services.<sup>6</sup> Nevertheless, taking full advantage of the opportunities offered by digitalisation is one of the biggest challenges national healthcare systems are still facing.<sup>7</sup> While some countries such as Estonia and Finland are pioneers in the field of digital health solutions,<sup>8</sup> other Member States struggle to keep the pace and introduce the required changes in terms of digital infrastructure, professional training and citizens’ empowerment and education. This can be due to, among many other limitations, health inequalities in the EU.<sup>9-12</sup> Therefore, potential biases among Member States should be reduced through adequate implementing measures. Despite EU citizens’ willingness to access their personal health data online in order to share such data and provide feedback on the quality of treatments,<sup>13</sup> most only possess partial knowledge of their rights regarding cross-border healthcare<sup>14</sup> and fewer than half of the EU Member States’ National Contact Points (NCPs) provide adequate information on citizens’ rights in obtaining healthcare in other Member States.<sup>15</sup>

In the light of the historically upward trend in citizen mobility, the advancement of digital technologies and, more recently, the COVID-19 pandemic, it has become more urgent than ever before to ensure that health policies and healthcare systems across the EU are more interconnected and interoperable, as well as accessible to healthcare professionals (HCPs) and citizens.<sup>16</sup> To this end, the Committee for Interconnected Care calls attention to the existing cross-border health data sharing and portability barriers. In order to enable the safe, efficient and practicable accessibility of personal health records across Europe, the EU policymakers should address these shortcomings with no further delay.



# RECOMMENDATIONS

## Pillar 1: Empowering Citizens to Benefit from Cross-Border Healthcare Opportunities

Directive 2011/24/EU<sup>4</sup> established a comprehensive set of patients' rights regarding access to health services in the EU. However, reports from the European Parliament<sup>17</sup> and the European Court of Auditors<sup>18</sup> concluded that the overall impact of such legislation on patients was limited. Given that the success of the Directive depends highly on citizens being aware of their rights, it will be necessary to put citizens at the heart of decision-making by complementing the existing channels of engagement.<sup>19-22</sup> Many healthcare systems are today under pressure due to a lack of preparedness and accurate data; educational elements must therefore be embedded into any digital strategy in the pipeline.<sup>23</sup>

### PROMOTE EUROPEAN AND NATIONAL CAMPAIGNS TO INCREASE AWARENESS ON CROSS-BORDER HEALTHCARE RIGHTS AND BENEFITS

Information needs are complex, especially when it comes to healthcare. A particular challenge is to find the right balance between providing comprehensive information and information that is meaningful and easily understandable to all citizens.<sup>24</sup> Educational campaigns at the regional and national level can contribute to increasing awareness amongst EU citizens and ensuring they understand how they can benefit from cross-border healthcare opportunities. The European Commission and Member States should focus on inclusive communication around citizens' rights in cross-border care, taking into consideration factors such as existing language barriers, as well as cultural and religious beliefs.

### LAUNCH OFFICIAL REGION-WIDE EDUCATIONAL PROGRAMMES ON CROSS-BORDER HEALTHCARE

The European Commission should launch region-wide educational programmes to place greater importance on citizens' rights and equip communities with the right knowledge on cross-border healthcare. Tailored days and events should cater to the diversity within countries and communities to convey key messages inclusively. Additionally, relevant stakeholders should be assembled, including citizens, HCPs and policymakers, to collect and exchange insights – for example, through debates, conferences and a generic digital template – allowing them to share use-cases, promote collaborative work and inspire decisive action towards enhancing the efficiency of cross-border healthcare in Europe.

### SUPPORT THE WORK OF NCPs IN IMPROVING COMMUNICATION AND INFORMATION PROVISION

NCPs play a critical role in providing reliable information and supporting citizens in making meaningful decisions when seeking healthcare abroad. Therefore, NCPs should guarantee a harmonised flow of information towards citizens by issuing practical guidelines and checklists. In collaboration with patient organisations, the European Commission should play a central role in the development of standardised, user-focused and user-friendly templates for application forms, with some free text options allowing citizens to tailor the information provided, which can be used by NCPs across the EU.<sup>25</sup>

### ENCOURAGE EUROPEAN REFERENCE NETWORKS (ERNS) TO ESTABLISH MULTI-STAKEHOLDER INTEREST GROUPS FOCUSING ON CROSS-BORDER HEALTHCARE<sup>26</sup>

The ERNs<sup>27</sup> interest groups on cross-border healthcare in Europe would facilitate best practice sharing on e-health, data collection, evaluation and monitoring, as well as contributing to strengthening citizens' engagement in cross-border health. These

groups should ensure a continuous bilateral flow of findings and learnings to national and regional stakeholders, for example through regional learning centres that also could act as shared space for local HCPs and policymakers to identify and solve practical challenges. This could result in higher efficiency, quality and cost-effectiveness of cross-border care across the EU Member States.

#### **ENSURE THAT HORIZON 2020 PROJECT OUTCOMES ARE PUT INTO PRACTICE BY PROMOTING END-USER CO-CREATION**

Co-creation and co-design with the end user are essential for developing a sustainable healthcare system in the EU. The lack of end-user co-creation results in 'patchwork', with too many digital health apps and tools which do not systematically assist the healthcare ecosystem, which leads to resistance from the end user.<sup>28</sup> The European Commission should support the outcomes of the Horizon 2020 projects Smart4Health<sup>29</sup> and InteropEHRate<sup>30</sup> that aim to develop, test and validate a platform prototype for citizen-centred health records (EU electronic health records, or EU-EHR). In using the platform, citizens would benefit from electronic healthcare record exchange and personal connected health services, and would be able to donate data to the scientific community.

## **Pillar 2: Increasing Access to Cross-Border Healthcare Through HCPs' Digital Literacy**

The success of a functioning cross-border health system depends, among many other factors, on HCPs and citizens alike. To educate citizens on digital health and data sharing, HCPs must be prepared and adequately trained in the use of digital technologies in healthcare. This can be accomplished through accredited Continuous Professional Development and Lifelong Learning Programmes, supported and coordinated by their professional groups. HCPs' digital health literacy and the involvement of NCPs are also very important prerequisites in the effective implementation of cross-border healthcare.

#### **ESTABLISH A SECURE EXCHANGE OF HEALTH DATA BETWEEN HCPs AND HEALTH INSTITUTIONS ACROSS THE EU**

National and local authorities should facilitate HCPs' engagement by preparing the appropriate infrastructure and providing access to available and usable technologies. In turn, the HCPs can support citizens with sharing personal health data under the guarantees provided by the General Data Protection Regulation (GDPR).<sup>31</sup> To build on the policy recommendations previously outlined by the Committee on Health Literacy and Self-Care,<sup>32</sup> this could be achieved by adopting patient-reported outcome measures, which is a regulated multi-level programme establishing standardised and controllable processes. Interprofessional collaboration within and among EU Member States is essential to establish a harmonised flow of information.



### **STANDARDISE CERTIFIED TRAINING PROGRAMMES ON CROSS-BORDER HEALTHCARE PRINCIPLES AND SECURE DATA-SHARING FOR HCPs**

The European Commission should ensure the development of standardised and mandatory e-learning curricula for HCPs, promoting group collaboration and providing equal opportunities to study across the EU. As a result, this would allow HCPs to enlarge their professional networks and exchange best practices with peers. Training could be expanded to include residency rotations, covering up to five stays in different EU Member States' health institutions. In addition, similarly to the Erasmus+ DISH project,<sup>33</sup> an exchange scheme on cross-border healthcare could be funded to support HCPs. This cooperation would foster knowledge and networking among HCPs, as well as generate and transfer expertise and experience between the institutions and organisations in various countries.

### **CREATE NATIONAL DIGITAL HEALTH HUBS ALIGNED WITH AN EU STRATEGY TO PROVIDE SUPPORT TO NCPs FOR EHEALTH (NCPEH)**

Communication between Member States' health systems and the eHealth Digital Service Infrastructure (eHDSI) would maximise uptake and encourage adoption among them.<sup>34</sup> Promoting bottom-up initiatives, such as through the EIT Health Fellowships Network<sup>35</sup> which increase awareness on cross-border rights and visibility of NCPs, could drive HCPs and their professional organisations to present programmes or projects that they identify with, helping to foster engagement with the concept. Moreover, HCPs should ensure they understand the competencies of NCPeHs and their latest directives, while also promoting NCPeHs' visibility to boost citizens' knowledge about their role in cross-border healthcare. Such a situation would be highly beneficial for all parties involved and should therefore be supported by the EU.

### **ACCELERATE THE INTEGRATION OF ADVANCED HCPs' PROFILES WITH OTHER DISCIPLINES**

Advanced professional functions and profiles are emerging at the intersection between healthcare and data science expertise. Professionals with scientific, mathematical and computational backgrounds and specialists in ethics, intellectual property and legal profiles of data use will see their roles expand, which could help to smooth the transition for the healthcare workforce as they cope with digital challenges. Integrating advanced roles in data science and engineering with pre-existing health and scientific knowledge across the healthcare environment will become crucial, and HCPs should be able to build their curriculum around this. It is essential to facilitate communication between IT and healthcare sectors and fund national university projects to create and promote courses such as process engineering, health informatics and data processing. Training opportunities for computer scientists, ethicists



and lawyers should be made available in the health sector. The EU institutions and Member States should prioritise actions aimed at deploying more and sustained investment to attract and retain talent in those fields – which is currently limited but needed for our national health systems.<sup>36-38</sup>



## Pillar 3: Creating a Reliable, Secure and Interoperable Health Data Sharing Infrastructure

The European Commission's Data Strategy plans to introduce legislative and non-legislative measures to create the European Health Data Space (EHDS) while helping to break down the silos when it comes to the portability of EU citizens' healthcare data.<sup>39</sup> EU data protection rules, such as GDPR and the ePrivacy directive,<sup>40</sup> ensure a high level of personal health data protection and security. Via the eHDSI, the delivery of cross-border services such as sharing patients' summaries and ePrescriptions is already a reality.<sup>41</sup> Other actions, like sharing laboratory reports and hospital discharge summaries, are imminent.<sup>42</sup>

### PROMOTE HARMONISATION OF DATA MODELS USED IN ELECTRONIC HEALTH RECORDS BY USING OPEN STANDARDS

The GDPR outlines the right to data portability, which depends on the possibility to receive the data in question "in a structured, commonly used and machine-readable format".<sup>43</sup> As such, data should be FAIR (Findable, Accessible, Interoperable, Reusable).<sup>44</sup> Further development of an Electronic Health Record Exchange Programme will be key to advance the "FAIRification" of data and prioritise information blocks enabling different use cases on cross-border healthcare.<sup>42</sup> A health data space infrastructure should enable seamless information sharing from one storage system to another (interoperability) so that different HCPs or institutions can utilise that information, not only for the purpose of care but also for health management, research or other legitimate purposes (Reusability).<sup>45</sup> More broadly, the EHDS should allow health data collected under common health data standards to be pooled, and should provide access to HCPs based on different levels of permission. Federated health databases allow access to sensitive data while minimising risks and unintended consequences.<sup>46</sup> Crucially, governance can reside with local entities, so that contextual dependencies surrounding data access

can be addressed in a more nuanced way and each healthcare institution retains responsibility for the use of its data, thereby making sure that ethical concerns and local privacy rules are respected.<sup>47</sup>

### **CONNECT PUBLIC EHEALTH DIGITAL INFRASTRUCTURES AND ACCELERATE APPLICATION AND TAKE-UP OF INTEROPERABLE EIDAS-COMPLIANT EIDS FOR HEALTH SERVICES AT CROSS-BORDER LEVEL**

Creating interoperable health identifiers for citizens would allow all health data associated with individuals to be traceable, giving citizens control over their health data, while in turn empowering them to proactively take care of their health. The European Commission should evaluate how to promote the application and take-up of such interoperable eIDs building on existing initiatives and sets of rules, including the Electronic Identification and Trust Services Regulation (eIDAS).<sup>48</sup> Only a harmonised adoption by Member States can ensure legal and operational interoperability when connecting different health systems to the eHDSI. DICOM<sup>49</sup> and HL7<sup>50</sup> are good examples of existing standards which have been broadly used to share different types of health data. The former, for instance, allows medical images to be shared in roughly the same way that one would share a picture in a JPEG format with friends and family.

### **DRIVE AN INTEGRATED, EU-WIDE APPROACH TOWARDS THE USE OF THE mHEALTH APP INTERFACE**

To make personal health data FAIR, it must be first easy to find and access (Findable and Accessible), both for citizens and HCPs. To achieve this, EU citizens could use an app-based interface, allowing them to upload, manage and control their personal health data, as well as access it through their portable eID. In the last few months, the world has seen the rise of many apps that use digital tracking to aid contact tracing in response to the COVID-19 pandemic, where citizens can report their symptoms and support the process of identifying people who may have been in contact with an infected individual.<sup>51-55</sup> Compliance with existing legislation should appropriately be taken into account, based on the type of data generated and the functions performed by the application.<sup>56</sup>

### **ALIGN HEALTH DATA INFRASTRUCTURE WITH GDPR BY CREATING AN EU CODE OF CONDUCT COVERING PRIMARY AND SECONDARY USE OF HEALTH DATA**

A code of conduct for health data,<sup>57,58</sup> adopted following a robust process of consultations of private and institutional stakeholders and after validation by the European Data Protection Supervisor,<sup>59</sup> should mirror the principles of lawfulness, fairness, transparency, purpose limitation, data minimisation, accuracy, storage limitation, integrity, confidentiality and accountability of data management laid out under the GDPR,<sup>60</sup> as well as serve the portability and accessibility of health data across the EU. It is of the utmost importance that data management is based



upon the data subject's dynamic consent. An EU-level supervisory authority could oversee the lodging of complaints against either a single EU data processor or each healthcare provider, so that possible occurrences of mismanagement, either at centralised or decentralised level, are dealt with at the source and before they turn into issues to be resolved through judicial remedies.

## INCENTIVISE THE CREATION OF AN EU ARTIFICIAL INTELLIGENCE (AI) ECOSYSTEM AND ADDRESS ETHICAL IMPLICATIONS OF USING AI AND BIG DATA

A federated health database could form the basis for generating insights and evidence from real-world clinical data. AI tools can enable progress if the right legal framework is set for their development.<sup>61</sup> In the perspective of full compliance with the current EU data protection regime, the use of data for scientific, statistics, and research purposes should take place in the framework of a liability regime where responsibility unequivocally stays with those designing, allowing and deploying AI techniques. Prevention and remediation procedures of breaches of ethical standards should be set upfront as a condition for authorisation. When relying on AI, the assumption should be that health data has been generated under a claim of confidentiality underpinning the relationship of trust between a patient on one side, and an HCP on the other.<sup>62</sup> As such, health data is conferred primarily for individual healthcare purposes, which should be respected as a matter of priority. The qualification of data concerning health as a “special category of personal data” means its processing, including through artificial intelligence and big data applications, is allowed only in limited instances provided for by the GDPR, such as for preventive medicine or public health purposes.<sup>63,64</sup>

## PRIORITISE CITIZENS’ CONSENT AS A BASIS FOR AI DEPLOYMENT AND LAY OUT DEDICATED AI AUTHORISATION AND MONITORING PROCEDURES TO ENSURE THE INTEGRITY AND SAFETY OF SOUND HEALTH DATA HANDLING

Automated individual decision-making is allowed, inter alia, in the presence of explicit consent by the data subject or in cases of substantial public interest, and provided that appropriate safeguards are put in place. Processing for “reasons of public interest in the area of public health” is admitted under specified conditions.<sup>65</sup> The COVID-19 crisis has provided a forceful demonstration of how both aggregated and individual data can be relevant in the fight against cross-border health threats. The obligation of professional secrecy is a fundamental safeguard in any such treatment and, although mainly regulated by national law,<sup>66</sup> should be a prerequisite for the conferral and sharing of data into an EU-wide infrastructure. As a further safeguard, the use of conferred data for automated processing should be subject to authorisation, granted after an assessment of the proposed methodology of treatment, the prospected safeguards and monitoring and the organisational integrity of the processor.



# CONCLUSIONS

Recent developments have demonstrated that it is more important than ever before to harness the potential of data and digital solutions to improve the health of European citizens. Cross-border healthcare calls for accurate and accessible health data sharing, which will allow for faster and improved diagnostics and care, advance research and innovation, and enhance overall healthcare outcomes. The ambitious EU4Health programme provides the necessary resources and opportunities to address the issues of data sharing and interoperability, creating a suitable environment for healthcare professionals and citizens to harness the benefits of health data.

Therefore, all citizens and relevant stakeholders should be actively involved in the decision-making process by collaborating with the EU institutions and ensuring that health data is harmonised and used to benefit EU citizens. Ultimately, the EU data protection legislation should be seen as enabling individual trust, rather than as an obstacle to change.



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# COMMITTEE FOR EUROPE AS A HEALTH INNOVATION HUB



## Europe: a Leader and World-Class R&D Innovation Hub for the Benefit of Patients, Healthcare Systems and the Economy

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**Seppe Kelchtermans**

# ENDORSEMENTS

Our committee would like to thank all consulted experts and organisations for their support, fruitful discussions and suggestions throughout the past months. This policy brief is a result of collaboration, hard work and dedication from the team members.

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



**Axel Voss**  
Member of the European  
Parliament (EPP, Germany)

“In these unexpected and unprecedented times of the COVID-19 pandemic, we have witnessed how health management measures have largely focused on each national member state instead of a common European approach. However, we can all agree that coordinated health measures and common EU projects can best serve our European citizens and the health care and economic systems of EU Member States. This also includes a European adaption of the Digital Strategy of the EU to the health sector to achieve a digital single health market.”



**Prof. Dr. Jörg Debatin**  
Chair, health innovation hub  
of the Ministry of Health,  
Germany

“The potential of personalised medicine aimed at optimised diagnostic and therapeutic strategies requires the availability of large pools of health data. These can only be achieved in a common European setting. Aiming to build a homogeneous architecture of fundamentals for research and innovation, I applaud the European Health Parliament initiative.”



**Dr. Kai Heitmann**  
Director Interoperability, health  
innovation hub of the Ministry  
of Health, Germany

“Making direct Patient Care data available to Research and Innovation is one of the prominent challenges. A European Health Data Space, embracing international open data standards and complementary appropriate funding can lead to well-suited solutions and will allow us to efficiently and quicker retro-feed findings and knowledge back for improved healthcare.”

# EXECUTIVE SUMMARY

To turn the European Union (EU) into a worldwide healthcare research and development (R&D) leader for the benefit of patients, healthcare systems and the economy, we investigated the current situation of R&D and the innovation landscape in Europe, determined challenges and ultimately developed recommendations for potential improvements.

Our findings indicate that it is of utmost urgency that the EU and its Member States overcome the fragmented innovation environment in order to transition to an even more innovative and inclusive landscape for all Europeans. We focus on three areas of imminent importance:

- 1. Translation of research from bench to bedside**
- 2. Fundamentals for research and innovation**
- 3. Data for research and innovation purposes**

In brief, we suggest actionable ways to tackle these issues.

**To accelerate translation from bench to bedside, we recommend to:**

- › Start an EU angel/venture capital investment agency
- › Incentivise all Europeans to help in forming and supporting an innovative landscape which prioritises research and healthcare
- › Harmonise the European legislation ecosystem

**To eliminate inequalities between Member States in terms of research and innovation, we recommend to:**

- › Harmonise health R&D funding across Member States, depending on their needs, to reach EU health R&D financing standards
- › Build a uniform approach towards boosting digital skills among all EU citizens, and specifically individuals across all healthcare sectors

**To solve issues regarding accessibility and data structures in healthcare we recommend to:**

- › Work towards building a European healthcare dataspace that promotes innovation
- › Secure accessibility of research and healthcare data by protecting patient data
- › Establish semantic and syntactic interoperability of healthcare data



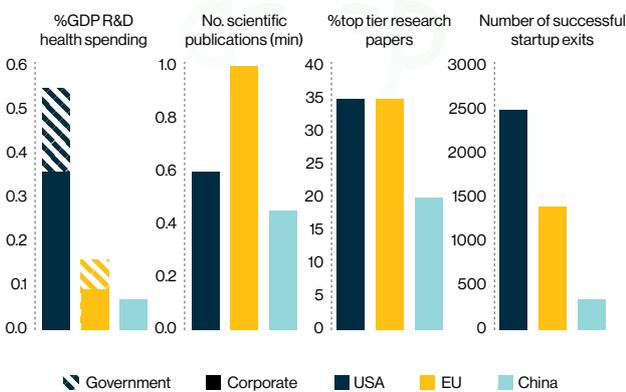
# INTRODUCTION

To become a better global healthcare R&D innovation hub, the EU must overcome its fragmented innovation landscape. We have identified three dimensions of issues as areas for potential future improvement:

## 1 Sub-optimal translation of research from bench to bedside

Even though the EU and European companies spend less on health-related R&D compared to the United States (US) in absolute and relative terms (relative to GDP or population), European scientists and institutions have published 40% more peer-reviewed publications, with quality on a par with their US peers.<sup>1,2</sup>

EU with efficient R&D output but lack of translation from bench to bedside



However, this does not translate into fully taking advantage of the potential commercial benefits that new academic innovations may hold. The EU has significantly been lagging behind other major regions, including the US, in terms of new start-up foundations and the number of successful start-up exits.<sup>3</sup> In many cases, research carried out in the EU is capitalised through US-based start-ups and companies. Consequently, the translation of new innovations into reality is a key area of future improvement.

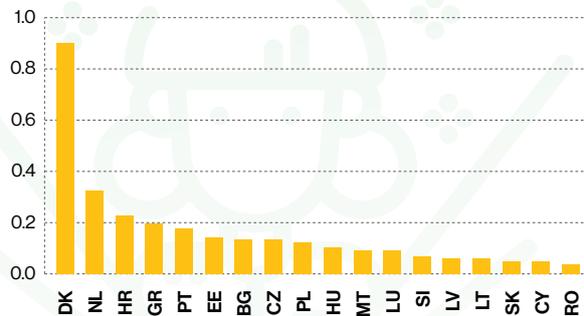
One aspect required for a viable start-up and commercial innovation landscape is an intellectual property (IP) ecosystem. We believe the EU IP system to be well-developed – but we see space for improvement to boost innovation further, demonstrated by the fact that more than twice as many biotechnology patents are being filed in the US versus the EU.<sup>4,5</sup>

Furthermore, the involvement of citizens in the innovation cycle up to the commercial stage should be improved: currently, the proportion of citizens of major EU Member States that have invested in public companies is significantly lower than other countries (e.g. only 12% of Germans own stock in public companies, in contrast to 50% in the US).<sup>6</sup> This limits the available capital for innovative companies, but also restricts the exposure and input the general population has to new ideas and business models.

## 2 Inequality of fundamentals for research and innovation

The amount that EU Member States are spending for health-related R&D as a proportion of their GDP varies significantly across the EU.<sup>7</sup>

%GDP Health R&D spending



It is clear that each Member State has different priorities and therefore different expenditure profiles. However, these differences affect health innovation, especially in countries with more limited national budgets.

Apart from direct spending for R&D, there is wide disparity in European citizens' preparedness for future technologies and innovation: more than 44% of Europeans lack basic digital skills, with dramatically high numbers in the workforce of low-income Member States.<sup>9</sup>

This poses a major challenge for the professional environment, which is evolving to rely more than ever on automation and digital tools, but more so for healthcare systems and innovative environments, where big data and complete connectivity will be the key drivers of change.<sup>9,10</sup>

### 3 Lack of accessibility and interoperability of data for research and innovation purposes

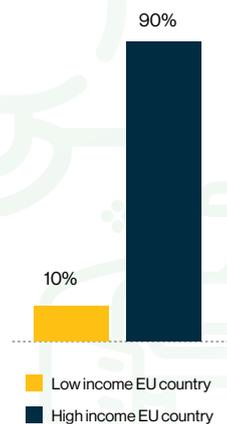
A digitally enabled workforce is a key pillar for innovation. However, the structure and availability of data is a crucial enabler on which such innovation can be built.

The European Commission and several European Council conclusions have stressed that the full potential of health data is not currently being used.<sup>11</sup> Our survey has demonstrated that researchers and companies in the EU see issues in three areas that must be addressed in order to build an increasingly efficient innovation hub:

- I. The available R&D and health data in the EU from patients, healthcare providers and research projects are completely unstructured or only partially structured;
- II. Institutions are reliant on third-party data as no access to structured health data in the EU is easily available;
- III. Outside of fixed collaborations, data and result-sharing is very limited. Only around 25% of all research projects share their research data outside of dedicated collaborations.<sup>12,13</sup>

All of these factors have a severe impact on progress and innovation, which can lead to research projects being abandoned, as well as hindering the development and testing of new health-related products and services.

Basic digital workforce skills



**44%**

**of EU citizens lack basic digital skills**

Lack of big data analytics causing unnecessary healthcare spending

Lack of scientific rigor in current generation of health apps

Lack of digital medicine training



# APPROACH

An extensive literature review, expert interviews and a Europe-wide online survey provided a robust basis to formulate a full view of the current state of healthcare innovation in the EU. This allowed us to identify hurdles and explore potential new avenues to accelerate innovation for the benefit of patients, healthcare systems and the economy.

Our recommendations are the result of critically analysing published articles and reviewing – sometimes contradictory – opinions. Moreover, our expert interviews covered all healthcare sectors: industry, academia and patients. Crucially, we involved multiple stakeholders for each of those segments. Our online survey, targeted at healthcare professionals in the EU (researchers, doctors, nurses, academic professors, industry representatives, etc.), helped us to obtain an up-to-date pulse check of the healthcare field and understand the unique perspective and opinions from people that are facing

diverse issues in their professions. A significant focus of our study was on data-sharing and current data structures, and the impact that these factors have on the ability to efficiently carry out projects or bring healthcare products to market.

These primary and secondary sources provided the basis for the development of our own ideas and suggestions, which we formed through a structured hackathon in Brussels, as well as during several brainstorming and design sessions involving all Committee members throughout the past year.

We believe our comprehensive approach serves to frame our recommendations in a way that considers inter- and intrarelations between innovation, patients, healthcare systems, and how the EU can benefit the most to become a world leading healthcare R&D innovation hub.



# RECOMMENDATIONS

Based on our analysis of the status quo of healthcare R&D innovation, we have developed the following three recommendations with specific suggestions on how to implement them.

## Boost translation of research from bench to bedside

The outputs from public research should be far more closely intertwined with private entrepreneurial activities being explored in the EU.

In order to maximise the commercial potential of R&D activities across the EU, we suggest the following:

### START AN EU ANGEL/VENTURE CAPITAL INVESTMENT AGENCY

- › Start an EU-wide scheme where a separate EU innovation investment agency can act as an angel or venture capital investor for pre-revenue companies. Its mission would be different to pure academic funding and more focused on translating ideas into commercially viable business models. It may be possible that existing bodies, such as the European Innovation Council or the European Institute of Innovation and Technology, could take up this role – but it should be separate from the policy and R&D funding arms of those bodies.
- › Provide funding in return for equity in start-ups, which will allow the EU to benefit from successful investments much more than it does currently. In turn, this will allow the EU to invest at greater scale and therefore push its innovation landscape forward.
- › This innovation investment body would work by screening the EU's early start-up landscape and investing in promising start-ups with a focus on the topics which are relevant and important for healthcare innovation. In addition, certain priority areas could be defined which promote specific calls for action, including for communicable diseases, antibiotic resistance or cancer treatment.
- › In order to increase public involvement in the EU's innovation drive, a funding cycle or specific calls for action could be made public and more transparent. This could be done via an open format on TV for instance, or through social media and online streaming similar to existing formats such as "Dragons' Den".



To bring the public closer to innovation, we need to foster and retain the involvement of people who are interested in a certain technological advancement or product and will actively support it.

We need to include the public in the circle of innovation and help them to invest in it.

### **INCENTIVISE ALL EUROPEANS TO HELP IN FORMING AND SUPPORTING AN INNOVATIVE LANDSCAPE WHICH PRIORITISES RESEARCH AND HEALTHCARE**

- › Organise open calls via online platforms for the public to ask for certain healthcare solutions or to name the issues they would like the EU to invest in next.
- › Provide tax benefits for all Europeans to invest in innovative European publicly traded companies, including biotechs, healthcare companies and health tech start-ups. This could be accomplished by reducing capital gains taxes or introducing a tax credits scheme, for example. A scheme which financially supports healthcare innovation in the EU, while also rewarding citizens, would be an important step towards including citizens in the EU's growth and future trajectory.
- › Establish EU trade fairs specifically targeting the public in order to familiarise them with innovative companies and new technologies. These fairs could include elements such as award schemes for citizens who propose innovative solutions and are interested in helping a company solve a problem or getting involved in various programs as external collaborators. That would boost creativity and bring the public close to the industry product development stages.

Possible solutions to improve the European IP system can include:

### **HARMONISE THE EUROPEAN INTELLECTUAL PROPERTY ECOSYSTEM**

- › Further harmonisation of IP law, streamlining procedures, increasing transparency on prerequisites for patent applications, and externalising patent standards to third countries via FTAs – all while considering the differing levels of economic development among Member States.

These actions could stimulate economic growth and attract investments in R&D as patents are a key instrument for innovation policy.<sup>14,15</sup> However, we acknowledge that these solutions are not necessarily actionable options and must be seen in a wider context. For example, they could be most effective when combined with regulatory improvements and with well-developed competition standards.<sup>16,17</sup>



The EU already addresses IP issues in a variety of ways. The most notable development has been the approval of a unitary patent and a Unified Patent Court (UPC) in 2012.<sup>18</sup> This package is expected to apply from the end of 2020 onwards. Considering the importance of patents, Supplementary Protection Certificates (SPC), and trade secrets for patient-centred pharmaceutical innovation, and in light of Europe's decreasing competitiveness on a global scale, several recommendations can be made to improve the IP landscape.<sup>19</sup> We call on the EU to:

- › Move forward with long-awaited initiatives, such as the Directive for a European Patent with Unitary Effect and the UPC Agreement creating a common court for European patents, as these steps would have great potential to shape a more uniform European patent landscape. Their entry into force would be a milestone towards IP harmonisation, and developments such as Brexit should not prevent the EU IP system from becoming more unified.



- › Further explore the possibility to create a unitary SPC, to reduce related application costs, reduce their complexity, and increase legal certainty and transparency. It is important to view the harmonisation of SPCs within the framework of the unitary patent and the prospective UPC to ensure a comprehensive approach towards patent applications.
- › Explore the harmonisation of patent co-ownership which would in turn facilitate open innovation processes.<sup>20</sup>
- › Increase judicial cooperation to reinforce convergence in the field of IP. The creation of the UPC would be a milestone in this respect. However, it might also be possible for EU Member States to promote judicial dialogue on patent litigation by establishing official lines of communication.<sup>21</sup> This would also facilitate the workings of the UPC upon its activation.<sup>22</sup> Finally, judicial cooperation has the potential to stimulate convergence in IP domains like trade secrets, where a 2016 directive has provided for harmonisation. The creation of a formal channel for judicial coordination and cooperation would benefit the European health R&D sector by improving transparency and legal certainty.
- › Balance IP protection, especially where patient access might be under pressure. This means that more stringent protection does not necessarily lead to optimal conditions for patients. As such, patients should remain the key beneficiaries from an innovative European health industry.

While we acknowledge that convergence of IP systems into one uniform system remains a controversial topic, we suggest that EU Member States should work together towards common solutions and agreements to unify the IP system. This step forward would allow innovators to secure easier access to patent applications, saving time and costs, while bringing innovation faster to patients across Europe.

# Equalise fundamentals in research and innovation across Member States

- › Bring together tech or industry in one country with research labs in other EU countries to eliminate the R&D funding differences between Member States and form intra-country hubs. This would not only boost competitiveness at the local and regional level, but also strengthen links in investments across countries.

We urge the EU to:

## HARMONISE HEALTH-RELATED R&D FUNDING ACROSS MEMBER STATES DEPENDING ON THEIR NEEDS TO REACH EU HEALTH R&D FINANCING STANDARDS

- › Assist Member States in creating medical innovation hubs. The EU could hold a supervisory role to set up procedures for these hubs, which could be made possible as a Joint Undertaking or as an extension of the Innovative Medicines Initiative (IMI). The EU's role would be to help facilitate information-sharing and the selection of promising projects, while accelerating the commercialisation process by connecting projects with a team of product development experts with close ties to the private sector.
- › If it is not possible to appoint a European supervisor through the normal legislative channel(s) for funding or competence reasons, such as failing to meet the subsidiarity requirement or flagging security or strategic interest concerns, there are two further alternatives. The first is an intergovernmental agreement between the Member States, establishing a similar framework of regional hubs with a supervisory coordinator; the second is notifying the European Commission of their intention to set up coordinated hubs, according to the Enhanced Cooperation Procedure (Treaty on the Functioning of the European Union, Articles 326-334).
- › The structure of regional hubs would help foster innovation and creativity in collaborations between the public and private sectors. Hospitals, research centres and health tech-related companies could belong to the same hub in close proximity with each other for daily interactions and intertwined interests and projects.

## BUILD A CONSISTENT APPROACH TOWARDS BOOSTING DIGITAL SKILLS AMONG ALL EU CITIZENS, AND SPECIFICALLY INDIVIDUALS ACROSS ALL HEALTHCARE SECTORS

Nine out of ten jobs will require digital skills, and healthcare will be no exception.<sup>9</sup> There is also significant evidence that the digital skills gap hinders healthcare innovation in developed countries.<sup>11</sup> We need to now lay the groundwork for the next generation of digital health entrepreneurship, build out unique skillsets to secure capital for innovation funding, and ensure the medical profession is well-prepared to digitally transform their industry.<sup>23</sup>

We propose to:

- › Build digital healthcare into the curriculum of healthcare professionals. There have been recent advancements in discussions where professionals proactively requested changes to the curriculum.<sup>24-26</sup>
- › Create a new specialisation in digital healthcare, so that these professionals can work alongside peers with other medical specialisations. This way, each professional can have confidence in their colleagues' medical and digital expertise.
- › Incorporate big data analytics into hospitals and patient care to minimise unnecessary healthcare spending. A recent study suggested that big data analytics can enable savings worth hundreds of billions of euros (e.g. \$300 billion per year in the US).<sup>27</sup> A key requisite for realising the potential of medical-related big data analytics, however, is that analytics is integrated into medical school curricula.



- › Empower data scientists and enable them to work together with medical professionals. This could be facilitated by creating data centres which are allocated to individual hospitals or clusters of hospitals, national bodies, or in regions across Member States. In these data centres, patient data would be jointly analysed by a team comprising data scientists and doctors.

We acknowledge that each expert has their own specialism, from analytical data scientists to biologists and medical doctors, and we therefore think that collaboration across all fields will lead to the greatest benefits for patients. We also think that each expert should have the skillset to be able to communicate with each other and to apply newly developed solutions (to a certain degree). To do so, the EU should prioritise boosting digital skills among healthcare experts and also among EU citizens. Currently, almost 50% of EU citizens lack basic skills; this would need to change in order for EU citizens to use and benefit from advancements in healthcare innovation.<sup>9</sup>

## Improve healthcare data accessibility and structure

### WORK TOWARDS BUILDING A EUROPEAN HEALTHCARE DATASPACE THAT PROMOTES INNOVATION

To improve the accessibility of health data, the European Commission's strategy for data should be amended to incorporate an open-data approach, including:

- › Create an EU Research Data Centre. The centre would collect and bundle public health data from all Member States, for example using national registries, and make this data available for research institutions. This would depend on the level of data that Member States would consent to sharing. In addition, the EU Research Data Centre would coordinate the European Open Science Cloud (EOSC) and provide synthetic and aggregated data for research and training purposes. Further initiatives include:

- › Assessing the possibility to introduce a European solution for patient data donation (through a Code of Conduct – Article 40, GDPR), approved by the European Board of Data Protection (EDBP).
- › Stress the importance of open standards and open interfaces, i.e. Application Programming Interfaces (APIs), in order to retrieve data from data silos. The European Commission should publish recommendations for the usage and implementation of APIs.

### SECURE ACCESSIBILITY OF RESEARCH AND HEALTHCARE DATA BY PROTECTING PATIENT DATA

- › Healthcare workers and research scientists in academia and industry need to have access to structured healthcare data based on international standards. This would allow them to use this data while pursuing further developments in research projects and while developing innovative solutions for patient health problems. The following measures need to be adopted:
  - » The EOSC should accept research data in different formats in order to form an open European research repository dedicated to research data.
  - » Utilising the most recent artificial intelligence and database structuring platforms. We suggest unifying the format and the data structures of all stored research data. The research data should also be categorised based on the research domain and data type.
  - » Making it compulsory for research data from all European health research projects to be shared – after satisfying the GDPR constraints – and uploaded to the EOSC for further use for other European research projects. The exception from this obligation would be if there was a conflict of interest, such as patent applications.

A European repository would not only be useful for sharing research data, but also as a reference to decision-makers who select which European projects to fund. It would help to ensure valid project objectives and would allow the project's outcome versus its goals to be assessed from a data perspective. Having a standardised data structure and format would make it quicker, easier and cheaper for researchers and EU decision-makers to access data.

### ESTABLISH SEMANTIC AND SYNTACTIC INTEROPERABILITY OF HEALTH DATA

- › This involves data across all healthcare stages, from bench to doctor's visits. The European Commission should draft and launch a coherent European Semantic Strategy to boost syntactic and semantic interoperability, so that the full potential of the European Digital Single Market can be realised. Part of this Semantic Strategy could be:
  - » Promoting the use of international standards such as SNOMED-CT and Fast Healthcare Interoperability Resources (FHIR).
  - » Developing and adopting recommendations for interoperable formats for ePrescription/ eDispensation, hospital discharge reports, EHCRs, European standards for data sets, data models and documentation (on the basis of the refined eHealth European Interoperability Framework).
  - » Allocate funding (via the European Regional Development Fund, the European Social Fund, DEP and HE) to research projects or national digital services that ensure interoperability and accessibility of data using international standards. Member States should be encouraged to digitise their health services and outcomes of health-related research projects (such as healthcare records, prescription, R&D data, etc.) and have access to European funding if they use international and interoperable standards.

# CONCLUSIONS

European health innovation has seen significant progress in the last decade and patient health has been made a top priority. Digitisation of the healthcare sector has been granted the highest attention, especially against the backdrop of the COVID-19 pandemic. However, there is room for improvement to transform the EU into a world-leading health R&D hub. We are convinced that through boosting innovation, our healthcare systems will be personalised to every patient's needs and accessible to everyone. Research and development of new ideas and technologies will

thrive and bring beneficial disruptive approaches to meet every individual's needs. By analysing the status quo in the EU's healthcare innovation landscape, we identified possible challenges and barriers that hinder further acceleration of innovation. We believe that our proposed solutions and recommendations will equip the EU with the necessary measures to boost its health innovation capacity. We call upon the EU to assess and incorporate our policy recommendations in order to further support patients, institutions, and the economy, while addressing societal challenges.



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# COMMITTEE FOR SUSTAINABLE AND HEALTHY LIFESTYLES



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- › **Alba Godfrey**, Project Officer, EuroHealthNet
- › **Patricia Loncle**, Professor of Sociology at EHESP, Head of the Research Chair on Youth
- › **Luis A. Morena Aznar**, Professor of Public Health at the University of Zaragoza
- › **Jacqueline Bowman-Busato**, EU Policy Lead, European Association for the Study of Obesity (EASO)
- › **Eloise Ryon**, Chief Executive Officer, Young European Leaders (YEL)

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

# ENDORSEMENTS



**Sofia Ribeiro**  
Monitoring Committee, Youth Health Organisation

“This document features a comprehensive set of policy recommendations that highlights the priorities for a healthier EU. This proves that young professionals are fully capable and invested in preparing a better future, and most important of all ready to start making it a reality.”



**Robert Madelin**  
Chairman and Chief Strategist  
FIPRA International

“This paper sets out an exemplary vision of joined-up policy-making. The call for Health in All Policies is a must, and sits well alongside the call for a sustainable and healthful food-chain, and for sustainable and healthy cities. A green EU recovery will need this stronger dose of health thinking.”



**Federation of the European Sporting Goods Industry (FESI)**

“While Europe is facing one of the biggest health challenges in its history, it is essential to give a voice to the new generation that will suffer the consequences of past decisions. Through these recommendations, youth urges decision-makers to concretely shape a healthier, greener and more resilient society.”



**Jutta Paulus**  
Member of the European  
Parliament (Verts/ALE,  
Germany)

“European Health Parliament’s recommendations take into account the complexity of measures necessary for a comprehensive European health policy. We need best practices for the prevention, treatment and recovery of patients, but also investments into research. Health policy is strongly interconnected with other policy areas: only if we push for ambitious environmental policies including agricultural practices and industrial activities, we can achieve healthy food, good drinking water and a non-toxic environment for our citizens and for our environment. Health must be regarded as a value in itself, not just as a means to an end!”



**Sara Cerdas**  
Member of the European  
Parliament (S&D, Portugal)

“In a time where the world woke up for the true importance of health in our societies, special attention must be given to the mental health and well-being of our citizen. We cannot fail to address the incumbent and increase of incidence of mental ill health and disease. A strategic work must be developed and focused in tackling this immense challenge, bridging close cooperation between the different stakeholders and the whole society.”



**Arlind Xhelili**  
Project Assistant,  
Collaborating Centre on  
Sustainable Consumption and  
Production (CSCP)

“The CSCP believes that progressive and effective pathways, be it policy or other action plans, towards achieving the SDGs and reaching a higher share of healthier and sustainable lifestyles, are dependent on multi-stakeholder, holistic and systemic approaches. Thus, we welcome the initiative of the European Health Parliament as well as further encouragement for the younger generation to participate more in related dialogues and share their vision on how such pathways can be collaboratively and inclusively built.”



**Caroline Costongs**  
Director EuroHealthNet

“Health promotion and prevention, as well as a Health in All Policies approach, are crucial to ensuring inclusive and resilient health systems and societies. I am pleased to endorse the recommendations of the Committee for Sustainable and Healthy Lifestyles, that also take forward the learnings of our INHERIT research initiative on how to foster healthy, sustainable and equitable living, moving, and consuming.”



# EXECUTIVE SUMMARY

The Committee for Sustainable and Healthy Lifestyles believes that European policymakers have great potential to promote healthy and sustainable lifestyles widely across policies. Healthcare is only one of the contributing factors to our health. Factors such as food, air quality and mobility play a major role in the health and wellbeing of European citizens. To include health in more policies in a sustainable way, there is a need to promote more meaningful youth participation in EU health policymaking. This also requires an empowerment of European citizens, and especially its youth, to play a more active role in its own health.

Based on several expert consultations, a comprehensive literature review and a self-conducted survey of 114 young people from 35 countries in Europe, we advise European policy makers to implement novel, inclusive and future-oriented policies to:

- › **Build a health inclusive Europe.**
  - » Deliver a Health in All Policies Approach.
  - » Adopt Sustainable Development Goal 3 in health policymaking.
  - » Adopt Health Impact Assessments (HIA) as standard.
  - » Strengthen Youth representation and participation in EU health policymaking.

- › **Create healthy and sustainable living environments and behaviours.**

- » Make healthy, sustainable food accessible, attractive and affordable for all.
- » Ensure green and sustainable living environments.
- » Promote active and sustainable mobility and the measures needed to encourage and enable this.
- » Ensure effective tobacco control measures.

- › **Empower citizens and young people to adopt a healthy and sustainable lifestyle.**

Our 25 recommendations target specific policymakers and EU institutions and bodies, and include a citizen and patient-empowering message valuable at a global level.



# INTRODUCTION

Obesity, diabetes, cardiovascular diseases, cancer and mental health problems are complex, multifactorial diseases with genetic, behavioural, socioeconomic and environmental origins that pose a major challenge for our society. The COVID-19 pandemic has shown that individuals with some of these pre-existing diseases have been disproportionately affected by the virus and its consequences. People from a lower socio-economic background and certain occupations have also been at a higher risk of infection. COVID-19 provides us with a specific lens, through which these health inequities have been brought to the public attention, but they are not new.

We urge policymakers to realise that the prevalence of many non-communicable diseases can be drastically reduced through preventive measures. For example, by ensuring clean air, facilitating access to healthy food, stimulating physical activity and eliminating the most harmful habits such as tobacco smoking. Yet, on average less than 3% of health expenditure goes to prevention,<sup>1</sup> missing out on the opportunity to reduce their impact on our overburdened healthcare systems.

It is increasingly important for policymakers to not only focus on treatment, but also on creating the right framework to empower healthy and sustainable lifestyles.

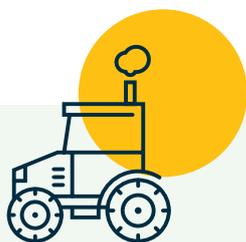
As members of the Committee for Sustainable and Healthy Lifestyle, we represent young Europeans and our shared and increasing concern about health and wellbeing. Young people want to take part in shaping a healthy future, but they face some major barriers, among others the lack of appropriate knowledge.

A survey conducted by our Committee revealed that one third of young Europeans considers lack of information as a major barrier in adopting a healthy and sustainable lifestyle. Results from another survey in eight European countries showed that almost 50% of respondents had insufficient or limited health literacy.<sup>2</sup>

We need to learn from the impact of the COVID-19 pandemic and use this unprecedented opportunity to create a healthy and sustainable future for Europeans. A number of already-proposed EU programmes and strategies aim at achieving this goal, such as the European Green Deal, the Farm to Fork Strategy and the EU4Health Programme. However, EU health policy still remains fragmented and lacks strong coordination. Often it does not use its full potential when it comes to disease prevention and health promotion.

We call on the European Union to apply the Health in All Policies approach and create the necessary legislative framework to ensure that a healthy and sustainable lifestyle is available to all. To make these efforts sustainable in the long-term, we ask for qualitative and meaningful youth engagement in the democratic and legislative process. Implementing our policy recommendations will bring Europe a big step closer to ensuring its children will live in a healthy and sustainable Europe.

# APPROACH



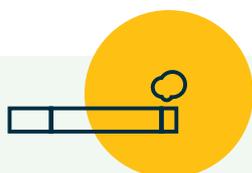
Agriculture is responsible for some 90% of EU ammonia emissions – a major contributor to the air pollution that kills 400,000 Europeans each year.<sup>3</sup>



Over 50% of the European population are overweight and more than 20% are obese.<sup>4</sup>



Doubling the current level of cycling would prevent 30,000 premature deaths with indirect economic benefits amounting to €78 billion per year.<sup>5</sup>



Over 700,000 EU citizens a year are killed from tobacco-related illnesses<sup>6</sup> – a habit which 29% of young Europeans still practice.<sup>7</sup>



The WHO European Region has the highest proportion in the world of total ill health and premature death due to alcohol.<sup>8</sup>

In addition to a comprehensive review of the literature, the Committee on Sustainable and Healthy Lifestyles conducted an online survey asking young Europeans how they value and engage with healthy and sustainable lifestyles; whether they would like to be more involved in decisions made about society's health; and what they think the EU could do to improve and promote healthy and sustainable lifestyles. The responses from a total of 114 young people across 35 European countries guided and informed our recommendations.

We also engaged with experts and stakeholders, including EU representatives, non-profit organisations, industry, academics and patient groups, on topics such as public health and prevention, youth engagement and sustainability.



# RECOMMENDATIONS

## Building a Health Inclusive Europe

### DELIVERING A HEALTH IN ALL POLICIES APPROACH

Our health is heavily influenced by our social and physical environments. It is estimated that formal healthcare only contributes 10% towards your health – there is so much more which determines our health and well-being outcomes.<sup>9</sup> Governance and policymaking beyond traditional healthcare therefore has enormous potential to promote healthy and sustainable lifestyles, and health and well-being considerations should inform policies and decision-making across sectors.

**Recommendation 1:** We call upon the European Commission, the European Council and the European Parliament to provide strategic leadership and embed the Health in All Policies Approach (HIAP) across all EU policies, programmes, and financial instruments, and to facilitate the translation of regional and municipal successes in applying a HIAP approach to national policies.

**Recommendation 2:** In doing so, policymakers should take into account the manifesto calls of “All Policies for a Healthy Europe”<sup>10</sup> and build on the EU 2030 Agenda for the Sustainable Development Goals (SDGs),<sup>11</sup> on the OECD’s framework for Policy Action on Inclusive Growth,<sup>12</sup> and on the work of the Finnish EU Presidency for the “Economy of Well-being”<sup>13</sup> and for “Health in All Policies”.<sup>14</sup>

### ADOPTING SUSTAINABLE DEVELOPMENT GOAL 3 IN HEALTH POLICYMAKING

The European Commission has strong commitments to achieving the UN Sustainable Development Goals by 2030. Recently published strategies such as the ‘EU Green Deal’, Farm to Fork Strategy and the European Climate Law enshrining the 2050 climate neutrality objective are welcomed steps to ensure we deliver on SDG 3: ‘Good health and well-being: Ensure healthy lives and promote well-being for all at all ages’.

We believe that further steps can be taken:

**Recommendation 3:** Building on our recommendation to adopt a Health in All Policies Approach, we call on all EU institutions to adopt an SDG-centric approach to policymaking, with special consideration to SDG 3.



**Recommendation 4:** The EU should develop a clear implementation strategy, including specific targets for actors at EU and Member State level alongside monitoring and evaluation plans, to achieve SDG 3 and measure progress.

**Recommendation 5:** The new EU4Health Programme should support Member States in reaching the SDG target and in tackling the non-communicable diseases through funding and organising work on health determinants, disease prevention and health promotion.

#### ADOPTING HEALTH IMPACT ASSESSMENTS (HIA) AS STANDARD

Impact assessments can help to create effective policies, especially policies to improve health outcomes which are influenced by multiple determinants, shaped by different policies and involve multiple sectors. This is a recognised approach for other key factors (e.g. economic and environmental impact) but not standard practice for health.

**Recommendation 6:** We call on the EU to adopt Health Impact Assessments and become a world leader in effectively assessing the impact of its policies on citizens' health outcomes, in all fields (e.g. research, environment, agriculture, trade, transport, urban planning and cohesion policy) and with a long-term perspective.

**Recommendation 7:** For Health Impact Assessment of policies, programmes and projects to be routinely implemented, a legal basis should be created.

**Recommendation 8:** The EU should develop a robust HIA methodology including both quantitative and qualitative indicators, and invest in capacity-building and skills training in cross-sector working.



## Strengthening youth representation and meaningful participation in EU health policymaking

Young people are becoming increasingly engaged in shaping society; for example, across Europe they have been 'school striking' for radical climate policies. In the survey conducted by the Sustainable and Healthy Lifestyles Committee amongst European youth, 75.7% of respondents stated they want to be more involved in EU policymaking. And yet, 62% find they are not informed enough about EU action. Additionally, the vast majority consider a healthy lifestyle as crucial.

The EU is already committed to interacting and engaging with youth, through the EU Youth Dialogue and the EU Youth Strategy: these two important EU projects bring the European youth closer to the institutions. Both programmes are extremely valuable, and yet they do not sufficiently address health.

Therefore, we propose six actionable recommendations to engage young people in the EU health policymaking process in a meaningful, structured and inclusive way.

**Recommendation 9:** The European Parliament's Committee on the Environment, Public Health and Food Safety (ENVI) should commit to ensure that the voice of European youth is directly represented by inviting youth organisations to attend Committee hearings, present their opinions, and engage in dialogue with Members of that Committee during the passage of a legislative file.

**Recommendation 10:** During the European Commission's consultation phase, youth representation should be strengthened. We urge DG SANTE to reach out and give the floor to youth representatives during the consultation phase.

**Recommendation 11:** We urge that those European youth representatives who are consulted should be from diverse national, cultural and socio-economic backgrounds.

**Recommendation 12:** In delivering the above recommendations we recommend creating a feedback loop to ensure follow-up and give the youth an opportunity to see their impact.

**Recommendation 13:** The European Commission should support capacity-building for community participation at all levels of governance (e.g. through targeted training on the EU policy cycle), particularly in areas with less experience with engagement such as youth.

**Recommendation 14:** We believe the Youth Progress Index should become part of the Country Reports issued by the European Commission to review the quality of life for the youth. There is a strong need to look beyond data such as youth unemployment and GDP, to also look at health and well-being.

## Creating healthy and sustainable living environments and behaviours

We need to create healthy and sustainable living environments that empower and support citizens to adopt healthy life patterns. We believe a mix of incentives and policy measures on food, environment, behaviours and mobility can make a tremendous difference on our collective health and well-being.

### MAKE HEALTHY, SUSTAINABLE FOOD ACCESSIBLE, ATTRACTIVE AND AFFORDABLE FOR ALL

**Recommendation 15:** The Farm to Fork Strategy represents a key milestone for the future EU food production. We ask DG SANTE to strengthen the information to consumers on food labelling, taking into account the environmental footprint for each food product. Following the Better Regulation procedure, we call on DG SANTE to further develop 'sustainability labelling' to drive more healthy and sustainable diets.

**Recommendation 16:** We welcome the idea of establishing an EU Code of Conduct for responsible business and marketing practice in the Farm to Fork Strategy: for example, avoiding the advertisement of meat at very low prices or limiting the commercial advertisement of beverages and food that are high in sugar. Furthermore, we call on DG SANTE to take into consideration youth representatives during the development of the Code as relevant stakeholders.

**Recommendation 17:** We call on the European Commission to further reform the Common Agricultural Policy (CAP) to ensure it fully supports the transition towards sustainable, future-proof food systems, by making 'sustainable food and nutrition security' into one of the CAP's overarching objectives and phasing out health-incompatible EU subsidies (e.g., tobacco cultivation, wine promotion, intensive livestock farming).

## ENSURE GREEN AND SUSTAINABLE LIVING ENVIRONMENTS

**Recommendation 18:** The European Green Deal should pay specific attention to increasing people's access to green and blue spaces in urban environments. In addition, the Commission should support towns and cities to develop high quality Urban Greening Plans and provide subsidies for their implementation. Green spaces are important resources for people to be active, socialise and relax, supporting both physical and mental well-being. Green spaces also help reduce 'heat-island' effects and they stimulate biodiversity.

**Recommendation 19:** Further effective action should be taken by the European Commission to improve air quality by applying legislation on low/zero-emission zones and updating the 2008 Ambient Air Quality Directive following the EU Court of Auditors recommendations.

## PROMOTE ACTIVE AND SUSTAINABLE MOBILITY

**Recommendation 20:** The EU should play a more active role in encouraging cities to implement Sustainable Urban Mobility Plans that support measures to reduce car use and promote walking and cycling. EU investment and funding programmes to prioritise and support sustainable mobility initiatives should take health into consideration.

**Recommendation 21:** We recommend that the Commission for Health and Food Safety and the Commission for Transport form a joint working group to adopt the Pan European Master Plan for Cycling Promotion. A joint funding scheme can encourage pertinent sectors in EU Member States, across levels, to design transport-related policies that deliver 'triple-wins' and work together across sectors to deliver these. Funding can also come from EU Structural and Investment Funds, or tailor-made support from the EU Structural Reform Support Service. The Commissions can also refer to this master plan through the European Semester cycle and its Country Specific Recommendations.

## ENSURE EFFECTIVE TOBACCO CONTROL MEASURES

**Recommendation 22:** We recommend that the European Commission and European Parliament seize the opportunity of the forthcoming reviews of the Tobacco Products Directive and the Tobacco Products Excise Duties Directive to tackle tobacco, the single biggest cause of preventable death. This could involve tougher tobacco control measures including higher taxation, advertising restrictions, and regulation of novel tobacco products combined with an EU-wide health campaign and approach to promote proven cessation methods.



## Empowering citizens and young people to adopt a healthy and sustainable lifestyle

Adopting a sustainable and healthy lifestyle requires not only supportive environments, but also skills, knowledge and personal capacity. These two elements are interlinked and mutually reinforcing. Health literate societies can play a more active role in self-management of health, resulting in improved prevention, adherence to healthier and more sustainable lifestyles and better health outcomes in the long-term.

In order to meet the societal needs and build on the EU-funded actions in this field, the Committee recommends the following:

**Recommendation 23:** The next EU budget should upscale investments in the development of health literacy at all stages of life to ensure that people have the skills, capacity and knowledge to navigate their lives in a healthy and sustainable way, with a focus on children, adolescents, more disadvantaged socioeconomic groups, migrants, ethnic minorities, and people with long-term health conditions.

**Recommendation 24:** Educational programmes on healthy and sustainable lifestyles are strongly needed. The young generation needs to be sufficiently literate in relation to health: physical exercise, rest/sleep time, nutrition, and how to apply better understanding and health literacy to self-management of certain conditions.

**Recommendation 25:** Promote and invest, via EU funding programmes such as ESF+, in digital skills for health in society. This will enable people to access and critically interpret online information to make informed health choices, and successfully use the increasing range of available digital health solutions.



# CONCLUSIONS

**This bold set of recommendations demonstrates the many ways in which policymakers are instrumental to healthy and sustainable societies. The COVID-19 pandemic and its economic consequences exemplify the urgency to improve the conditions in which we live and work, in which Europe's youth grows up. We need to give people the tools to protect their physical and mental health. To ensure a prosperous and sustainable future, it is vital to hear the voices and challenges of our young population and integrate those insights into our policies**

**Implementing our recommendations will strengthen the resilience of our society. It will create a healthy and productive workforce that can support a sustainable economic recovery from the COVID-19 pandemic and will face the ongoing climate challenge by harnessing the potential of Europe's biggest asset: its people. Young Europeans call on their policymakers to rebuild better and smarter to empower Europe's next generation of health.**

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# COMMITTEE FOR TACKLING CANCER IN EUROPE



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This policy brief is a result of collaboration, hard work, and dedication from the team members.

# ENDORSEMENTS



**Anna Prokúpková**  
Advocacy & Project Manager,  
Association of European  
Cancer Leagues

“The 2019-2024 mandate opens opportunities for true change in terms of coordinated response to key issues in health and cancer policy. Europe’s Beating Cancer Plan, Horizon Europe’s Cancer Mission, the Pharmaceutical Strategy, European Health Data Space and the ambitious EU4Health Programme should ensure that the voice of cancer patients and society at large are at the core EU’s activities. Decision-makers should listen to young health leaders and guarantee the highest quality of health services while maintaining sustainability of healthcare systems for future generations. The recommendations suggested by the EHP Cancer Committee tackle some of the key challenges in cancer prevention and care delivery, and will certainly gain political attention in the years to come.”



**Alexander Roediger**  
Chair of the EFPIA Oncology  
Platform

“We have made great progress in cancer over the past 20 years, thanks to prevention, diagnosis, treatment and quality of care. 50% of skin cancer patients can expect to be alive 5 years after diagnosis. Ten years ago it was only 5 percent. Nevertheless, cancer is set to become the biggest disease burden because of demographic change, population growth and lifestyle. Active involvement of the next generation of policy makers is critical, and this report is a great example that there is not a single key to resolve the cancer challenge and that a single stakeholder alone cannot resolve it.”



**Charis Girvalaki**  
EU Affairs Manager,  
European Cancer Patient  
Coalition

“ECPC fully supports EHP recommendations on prevention, screenings, and tackling inequalities and social issues in cancer in Europe. We are delighted to see we are sharing a common vision on fighting for a Europe of equality, where all European cancer patients have timely and affordable access to the best treatment and care available”.

# EXECUTIVE SUMMARY

Cancer is a group of non-communicable diseases that represents the second cause of mortality in Europe. In 2018, according to the European Cancer Information System (ECIS), 1.4 million people in the European Union (EU) died from cancer.<sup>1</sup> The burden of cancer does not only affect individuals but also society as a whole and its economy, health and social systems, national budgets and productivity. What can be done?

In order to tackle cancer in Europe, a coordinated action is needed. The EU along with Member States and sub-national level bodies need to increase their collaboration to work towards improved availability, accessibility and affordability of cancer care. On top of that, cancer patients, survivors and their families should be put at the centre of any intervention to best take into account their experiences. Moreover, considering that 40% of cancers are preventable, it is urgent to tackle risk factors and put in place prevention measures across EU Member States to reduce incidence and leave no one behind. Finally, with the significant progress resulting from scientific development, the digitalisation of healthcare systems and the delivery of care could highly benefit cancer patients and research.

Therefore, the EHP Committee for Tackling Cancer in Europe calls on the involved institutions and stakeholders to reflect on the following areas:

- › **Putting prevention and screening at centre of cancer policies**
- › **Using digital tools and fostering cancer literacy for the benefit of patients**
- › **Acting toward a Europe of pioneers for real life data collection**
- › **Tackling inequalities and social issues in cancer**

In this framework, along with the flagship initiative launched by the European Commission “Europe’s Beating Cancer Plan”, we propose innovative but actionable recommendations that could make a difference in addressing cancer-related challenges.



# INTRODUCTION

As recalled by the President of the Commission, Ursula von der Leyen, on World Cancer Day 2020, cancer is something personal and everyone has experienced it, directly or indirectly.<sup>2</sup> Despite several developments both in terms of research and treatments, cancer remains a major health issue that needs to be tackled holistically and with a coordinated approach.

Since the 1980s, the European Union has always been quite active in the field of cancer policy. In particular, the new European Commission recently presented a flagship initiative to fight cancer: the Europe's Beating Cancer Plan. Its main focus lies on four main pillars, namely prevention, early diagnosis, treatment, and follow-up care. In this framework, the recommendations that we propose can complement the Europe's Beating Cancer by delivering concrete and pragmatic solutions to the several challenges that still exist regarding this burdensome disease.

Moreover, the European programmes financed under the new Multiannual Financial Framework (MFF) as well as other sources of financing will have a strong focus on health, as a consequence of the COVID-19 crisis. Therefore, addressing cancer through these tools would represent a major opportunity to reach concrete results in terms of research, prevention, care and survivorship.

Despite major efforts from the EU and Member States, large variations in cancer incidence, survival, and mortality still exist between countries and between social groups within countries. A large part of cancer inequalities could be prevented through coordinated action at many levels of policy and care. In addition, the systemic differences affecting an individual's exposure to risk factors and the likelihood of them developing cancer, as well as their access to screening, diagnosis, treatment facilities, and palliative care need to be addressed quickly and effectively.



# RECOMMENDATIONS

## Putting prevention and screening at centre of cancer policies

### FOSTERING PRIMARY PREVENTION TO IMPACT LONG TERM CANCER INCIDENCE

#### Joining forces to reduce cancer risk factors

Lifestyle factors including nutrition, alcohol and tobacco consumption are known to impact cancer incidence.<sup>3,4</sup> Despite a long history of prevention campaigns it is still estimated that up to 40-45% of all cancer cases are preventable,<sup>5</sup> demonstrating a continuing need to limit exposure to cancer risk

factors, notably the ones highlighted in the European Code Against Cancer.<sup>6</sup> With several ongoing EU initiatives focused on health or lifestyle, Europe holds the keys to become a leader in cancer prevention and monitoring with no increase in the overall health budget. It is thus proposed to join forces from the European Green Deal, including its Farm-to-Fork strategy, Horizon Europe and its mission focusing on cancer<sup>7</sup> and the European Health Data Space to foster primary prevention. A standardised impact factor could thus be added in all EU funded projects related to health or lifestyle to measure impact on cancer prevention. A systematic plan to collect data on cancer incidence and exposition to known risk factors would indeed be key to monitor the effectiveness of cancer prevention policies.

As highlighted in the interim report from the Cancer mission,<sup>7</sup> areas of research should first focus on alcohol, food and sugar sweetened beverages and tobacco consumption, as well as commercial determinants of health. Additionally, the European Green Deal, with its goal of a toxic free environment, represents a good opportunity to reduce carcinogen exposure in the environment and improve air quality, both of which are known to impact cancer incidence.<sup>8</sup> Moreover, the Farm-to-Fork strategy should raise awareness on the importance of a healthy diet and include a transparent communication strategy on nutritive value of food.

#### Addressing infection-related cancers

Hepatitis B (HepB) is a potentially life-threatening liver infection caused by the hepatitis B virus and represents a major global health problem. Although HepB can be prevented by a vaccine, WHO estimated that in 2015, 257 million people were living with chronic HepB infection. Of these cases there were approximately 887,000 deaths, mostly from cirrhosis and hepatocellular carcinoma.<sup>9</sup> With evidence of ongoing transmission within and between countries, sustainable vaccination programmes are essential in order to achieve the WHO target of hepatitis elimination by 2030.



Human papillomavirus (HPV) is a very common sexually transmitted infection which causes approximately 5% of all cancers and is implicated in nearly all cervical cancers.<sup>10</sup> Estimates vary concerning the role of HPV in other cancers, but evidence suggests that it may notably be the cause of the majority of oropharyngeal, anal, penile, vaginal and vulval cancers. Promoting HPV vaccination in young women and men is key to prevent HPV-related cancers which could ultimately have a significant impact on overall cancer incidence. Enhancing knowledge on HPV-related health risks is essential to increase awareness of HPV amongst the population, including the safety and high efficacy of vaccination and the value of HPV screening.

Overall, in line with WHO guidelines on HepB and HPV-related cancers, the European action towards cancer should have a clear goal to eliminate these infections (and others that are known to increase cancer risk) in all Members States. This requires including hard-to-reach communities (HepB) and having a gender-neutral approach (HPV).

#### **UPDATING BEST PRACTICE FOR CANCER SCREENING AND PROVIDING GUIDANCE TO ORGANISE DETECTION PROGRAMS**

The 2003 Council of the European Union recommendation on cancer screening,<sup>11</sup> which called on EU Member States to implement national screening programmes for breast, cervical and colorectal cancer, has led to substantial improvement in terms of cancer screening and harmonisation on best practices. However, the implementation of these recommendations is not optimal, and coverage varies substantially across Member States. Therefore continuous efforts to improve and standardise best practices in terms of cancer detection are necessary. Moreover, as medical knowledge is constantly evolving, regular updates of guidelines and common practices are crucial to adapt to scientific developments.<sup>12</sup> In particular, there are recent data supporting changes in breast, colorectal and eventually lung cancer screening.



#### **Breast cancer**

Screening for breast cancer has proved to reduce mortality from the disease. The International Agency for Research on Cancer concluded that population-based mammography screening is associated with cancer mortality risk reduction of approximately 40% in women between 50-69 years of age. There is (more limited) evidence of a 32% reduction in mortality risk in women aged 45-49 and 17% in those aged 40-44. Besides its proved efficiency, there has been an evolution in breast imaging technology. Digital Breast tomosynthesis (DBT), or 3D mammography, is rapidly replacing digital mammography. Not only does DBT have superior, or at least equivalent, performance compared to 2D mammography, it also enables a more accurate diagnosis for patients with dense breasts.

#### **Colorectal cancer**

In colorectal cancer, current recommendations cover screening for individuals aged 50 to 74. However, there has been a notable increase in colorectal cancer deaths in people aged under 55, which suggests a need to re-evaluate population age limits for colorectal cancer screening programmes.

## Cervical cancer

In line with the proposed strategy on primary prevention of infection-related cancers, the screening strategy of cervical cancer should be updated to include HPV tests, based on the high performance of this testing procedure and European guidelines.<sup>13</sup>

## Lung cancer

Lung cancer is the leading cause of cancer deaths in the European Union and while tobacco prevention must remain a priority to reduce lung cancer incidence, a systematic screening program would be an additional tool to tackle it.<sup>14</sup> Although lung cancer screening is not embedded in EU recommendations, recent data may however support

its implementation in high risk patient groups. The Dutch-Belgian Randomised Lung Cancer Screening (NELSON) trial published in 2020 indeed suggested a reduction in lung cancer deaths by 24% in high risk men, compared to patients who did not undergo screening.<sup>15</sup> These encouraging results support further programmatic research on how to implement systematic screening in practice. Additional analysis on cost-effectiveness as well as research on eligible populations, including women, would also be necessary to identify the population that would benefit the most from a lung cancer screening.

### Key recommendations on cancer prevention and screening

#### 1. Fostering primary prevention to impact long term cancer incidence.

- › In collaboration with the International Agency for Research on Cancer, joining forces from ongoing European projects to:
  - » reduce cancer risk factors, in particular in the fields of nutrition and the environment;
  - » eliminate infection-related cancers.

#### 2. Updating the 2003 Council recommendation for cancer screening and monitor its implementation.

- › Re-evaluating the age limits for cancer screening programmes, including colorectal screening, 3D mammography and cervical HPV screening.
- › Supporting further research on lung cancer screening with the aim of implementing systematic programmes in high risk patients taking into account resources, cost-effectiveness and practical aspects.
- › Providing technical and structural support for Member States to implement national screening programmes, even in the most deprived regions, and to maintain up-to-date training of healthcare professionals.
- › Publishing guidelines for national campaigns to reach people more at risk, such lower-income populations, by using clear messaging that incentivises participation.
- › Monitoring screening implementation in Member States by collecting data systematically.



# Using digital tools and fostering cancer literacy for the benefit of patients

## IMPROVING ACCESS TO DIGITAL TOOLS

Digital-native healthcare professionals and citizens make for effective and improved cancer care. In accordance with the interim report from the Mission Board for Cancer,<sup>7</sup> who propose to create a European Cancer Patient Digital Centre, the Committee recommends improving access to digital tools. Medical imaging, used to diagnose and stage cancer, indeed benefits from Artificial Intelligence (AI) through improved detection, characterisation and monitoring of the disease. It also fosters quality doctor-patient relationships by providing the practitioner with more time thanks to the automated prioritisation of imaging exams and generation of reports. However, the potential of Artificial Intelligence to improve cancer care essentially lies in the professional's ability to use new technologies.

The European Commission's 2018 Digital Education Action Plan aims to close the digital skills gap by laying out 11 actions for the development of digital skills.<sup>16</sup> Nevertheless, regional inequalities subsist. Therefore, further harmonisation and better access to high-quality AI training for all, including citizens, should be rapidly put in place. Indeed, AI applications and devices have the potential to reduce inequality gaps in cancer care by providing services to populations living in isolation or medical deserts by empowering citizens. In particular, the COVID-19 crisis showed that cancer patients were increasingly isolated and suffered from late diagnosis and treatment.<sup>17</sup>

## FOSTER CANCER LITERACY

This digital transition must be accompanied with a clear and transparent communication plan toward patient communities. Improving health literacy and education is indeed key to enhance patients' motivation and ability to make informed decisions in their care pathway.

More generally, a program to improve health and cancer literacy would be a prerequisite for a successful new prevention and screening plan.<sup>18-20</sup> It is important to make sure that these measures to increase cancer literacy are accessible to the general public and notably senior patients that have a higher risk of having cancer.

## EU FUNDING FOR THE EFFECTIVE USE OF ARTIFICIAL INTELLIGENCE IN CANCER CARE

The WHO's 2020 draft global strategy on digital health reports that a barrier to the implementation of national digital care models is funding. It highlights up-front costs for buildings, facilities and ICT, human resources and training among other things.<sup>21</sup> These elements must be taken into account, especially in the first phases of a full integration of Artificial Intelligence in healthcare.

Several EU funds can support the implementation of the necessary infrastructure and capacities. The Cancer Mission of the Research and Innovation programme Horizon Europe, the Digital Europe Programme and the ESF+, among others, should not neglect the potential of AI in improving cancer care accessible to all.

Moreover, as a result of the COVID-19 crisis, the EU has created a standing-alone programme for health, EU4Health, which will represent an additional opportunity to put in place concrete actions to tackle cancer.

## Key recommendations on digital tools

1. **Updating the Digital Education Action Plan towards health professionals and patients' communities to pursue further harmonisation between EU Member States.**
2. **Promoting cooperation between Member States to:**
  - › Exchange best practices in AI training and access;
  - › Elaborate on EU quality standards for digital education and training.
3. **Dedicating special funding for effective use of Artificial Intelligence in cancer care and to close inequality gaps between countries and systems with different economic developments.**

## Towards a Europe of pioneers for real life data collection

Population-based cancer registries are critical to providing information on cancer burden, occurrence and trends in a given geographic area. They rely on continuous and systematic collection of data from multiple sources to retrieve and gather together knowledge on cancer. Reliable data are notably critical to:

- › design and evaluate cancer control programmes;<sup>22</sup>
- › develop new interventions focused on patient's needs;
- › facilitate and accelerate drugs' approval and access;<sup>23</sup>
- › investigate risk factors a given community;
- › conduct studies on cancer prevention, early detection and screening, and care.

### MAKING BETTER USE OF THE EXISTING DATA THROUGH HARMONISED DATA COLLECTION PRACTICES

Data collection can contribute to reducing the burden of cancer and to using health resources more effectively.<sup>24</sup> However, to reach this objective, it is necessary to improve both the quality and the quantity of population-based cancer registries,<sup>25</sup> with the ultimate aim of creating a comprehensive population-based cancer registry at EU level. It is crucial that common rules, standards, methods and definitions are used to make data comparable. Although significant progress has been made, marked differences still exist between cancer registries and one-third of the EU population still lacks quality cancer registration.<sup>26</sup> The European Network of Cancer Registries<sup>27</sup> and the European Cancer Information System, could play a more substantial role in defining more detailed and extended common methods and standards for the data collection.<sup>28</sup>

To reach uniformity, it is fundamental that national statistical institutes, cancer institutes, hospitals collect and elaborate data in a comparable way and make them available in a timely manner. This could be achieved by the creation of "European guidelines for data collection on cancer" and by organising trainings for professionals working in the field.



The contribution of platforms and technological tools should be of help to concretely collect, store and compare data while creating reliable and high-quality population-based cancer registries. Moreover, applying a standardised statistical method to analyse population-based cancer data would save resources in the long-term and make the registries more efficient and accessible.

Patients must be put at the centre and successful implementation of cancer registries will empower them and encourage meaningful participation. In this sense, an ambitious transition towards the inclusion of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in a comprehensive population-based cancer registry at EU level is recommended to collect the patient perspective. Standardised questionnaires to collect data from patients should be designed, made available in all 24 EU languages and be easily accessible for patients, potentially through the development of a portable device App, which ensures a safe share of data.

#### **FOSTERING THE USE OF REAL-WORLD EVIDENCE FOR THE APPROVAL OF NEW MEDICINAL PRODUCTS IN SITUATION WHERE HIGHER UNCERTAINTIES ARE ACCEPTABLE**

Clinical trials are the most reliable tool for collecting evidence on the effectiveness and safety of new medicines. However, due to their limited external validity, data generated in clinical trials are not automatically applicable to the population treated in clinical practice. Additionally, the development of personalised medicine and targeted therapies in oncology can limit the feasibility of large randomised controlled trials in this therapeutic area.

While several initiatives were launched by the European Medicine Agency (EMA) with the aim of gathering evidence through real-life use to supplement clinical trial data and accelerate patient access to innovate therapies, these types of adaptive pathway are still largely underused.<sup>29</sup> Guidance on how to concretely collect and use real-world evidence to facilitate early and progressive patient access to a medicinal product remains limited.

With the rise of new technologies that enable the collection of massive amounts of information, there is the potential for researchers to change the way they collect data for clinical research purposes. It is thus proposed to create new guidelines on how to collect real-world evidence to accelerate medicinal product development in situations with a great unmet need, when the feasibility of a large randomised trial is limited. In addition, to meet the requirements of the regulatory agency these guidelines should be suitable for proper health technologies assessment (HTA) to launch new products at a fair price in all Member States with a risk sharing agreement. In that respect, the EMA qualification procedure<sup>30</sup> could be clarified and further elaborate, in cooperation with HTA bodies and patient organisations.

Long-term sustainability of early dialogues conducted in parallel with regulatory and HTA agencies<sup>31</sup> should also be ensured as they represent an optimal window of opportunity to reach agreement on proper evidence generation.

#### **Key recommendations on registries**

- 1. Harmonising practices in term of data collection with the support of the European Network of Cancer registries, the European Cancer information system and patients' communities towards the creation of a high-quality European dataset on cancer.**
- 2. Enhancing the use of patient disease registries for regulatory and HTA purposes in situations characterised by high unmet needs and limited feasibility of large randomised trials:**
  - › clarifying the use of the EMA qualification procedure in cooperation with HTA bodies;
  - › ensuring long term sustainability of early dialogues between the regulatory and HTA agencies to reach common agreement on evidence generation.

## Tackling inequalities and social issues in cancer

The global problem of social inequalities in cancer is well documented but unfortunately persistent.<sup>32</sup> In Europe, cancer care is not uniform across all Member States; there are large variations in cancer incidence, survival, and treatment access between countries and even within countries, between social groups. These inequalities, which have economic and social implications, could be preventable with concerted actions at European level.

### FOCUSING RESEARCH ON RARE AND PAEDIATRIC CANCERS

Rare cancers are often neglected diseases while in total they account for at least 20% of all cancers.<sup>33</sup> Inequalities in terms of research and development are even more pronounced for paediatrics. Indeed, each year, the parents of approximately 35,000 children and adolescents hear the words “your child has cancer”. The annual number of diagnosed cases has not declined in nearly 20 years. Despite some major

progress, most of these rare cancers are treated with off-label therapies as only a small percentage of cancer treatments are also approved in paediatric patients.<sup>7</sup>

To address this issue, and within the context of the ongoing EU pharmaceuticals strategy,<sup>34</sup> our Committee proposes to initiate an EU reflection for innovative and adaptative clinical trial design for paediatric cancers. In that respect, construction of European registries would be valuable as they could be used as external control for clinical trials when appropriate in accordance with ICH10 guidelines.<sup>35</sup> These registries are indeed not sufficiently developed in rare and paediatrics cancers. Orphanet recently highlighted that among the 753 registries for rare diseases that are available in Europe, only 38 cover rare cancers, while only three focus on children's cancers.<sup>36</sup>

Finally, updated regulatory requirements for drugs targeting rare and paediatrics cancers could also aim to better follow drugs in post-launch to make sure that the EU incentive schemes allow effective patients access in all member states.



## ADDRESSING MEDICAL AND SOCIAL ISSUES FACED BY SURVIVORS

Although follow-up after remission plays a central part in long term survival, survivors face many social difficulties impacting their rehabilitation and mental health.<sup>37</sup> Being cured from a cancer does not necessarily mean having an optimal health state as many survivors face fear of recurrence, psychological distress and possible long-term treatment side effects.<sup>38</sup> As there is an increasing number of innovative treatments, including new immunotherapies associated with potential cures in advanced setting, inequalities in survivorship might be further reinforced in the upcoming years.

Therefore, best practices to address social issues faced by survivors should be implemented at the European level to ensure equal access to quality survivorship care.

In that respect, the implementation of the recommendation on survivorship and rehabilitation from the Cancer Control Joint Action is highly supported.<sup>38</sup>

Additionally, under the remit of the European Agency for Health and Safety at work (EU-OSHA), new policies could be implemented to facilitate employment and professional rehabilitation of cancer survivors. National regulations in some countries could be promoted and used as example to harmonise practices in Europe. Regulations from Italy<sup>39</sup> and the United Kingdom<sup>40</sup> are notably good examples to facilitate employment and return to work for cancer survivors. Regulations on the right-to-be-forgotten implemented in Belgium, France or Luxembourg should be harmonised across all members stated to reduce the socioeconomic burden on cancer survivors by improving their access to loans and insurance.

## Key recommendations on inequalities and social issues

- 1. Updating regulatory approval requirements for rare and paediatric cancers, within the context of the ongoing pharmaceutical strategy for safe and affordable medicines, to promote new clinical trials designs and monitor that EU incentives effectively facilitated patients' access.**
- 2. Under the remit of the EU-OSHA, using national examples of regulations on employment and right-to-be-forgotten to promote harmonised European best practices on social issues faced by cancer survivors.**

# CONCLUSIONS

The COVID-19 crisis highlighted the urgent need for a stronger European cooperation to tackle major public health issues, including cancer. With a growing incidence, cancer has become the second leading cause of death Europe and its burden continues to globally increase at the individual and societal level. Although cancer is nowadays everyone's concern, inequalities and discrepancies are observed across European Member States, emphasising the importance of harmonised practices.

With the ongoing Beating Cancer Plan and Mission Board for Cancer, we believe that Europe holds the keys to become a leader in cancer care and prevention. This momentum is indeed a unique opportunity to efficiently and collectively tackle malignancies with an aligned strategy across health initiatives and key European stakeholders. In that context, and as highlighted in our recommendations, our Committee calls for a holistic and inclusive action plan going from prevention to survivorship while promoting early detection and treatment.



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# COMMITTEE FOR MENTAL HEALTH AND HEALTHY WORKFORCE



## Towards a Healthy Workforce in the EU – Implementing Actions for Sustainable Work Life

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- › **Christian Døsing Sørensen**, Specialist, Danish Committee for Health Education
- › **MD Meri Larivaara**, Senior Adviser, Mieli Mental Health Finland
- › **Riitta Sauni**, Professor of Occupational Health and Occupational Medicine, Tampere University
- › **Mental Health Europe (MHE)**

# ENDORSEMENTS



**Alviina Alametsä**  
Member of the European Parliament (Greens/EFA, Finland)

“Taking decisive action on mental health would improve the lives of millions of people in Europe. I endorse these highly important, research-based recommendations, aiming to promote mental health at work. In workplaces, we have protections against physical harm and injuries. We should treat psychosocial risks as seriously and take concrete steps to alleviate them. This would benefit workplaces, individuals, economy and the society as a whole. It’s time for strong mental health action!”



**Agnes Jongerius**  
Member of the European Parliament (S&D, Netherlands)

“Due to the COVID-19 crisis, a lot of jobs have changed greatly. Whether people had to suddenly work from home or even became (temporarily) unemployed, everybody was affected by the consequences of the crisis one way or another. One of the things that the COVID-19 crisis has taught us, is that we should not be blind to the psychosocial aspects of work. Instead, we should take this crisis as an opportunity to make the workplace a better and healthier place.”



**Alex Agius Saliba**  
Member of the European Parliament (S&D, Malta)

“Mental health affects all areas of life and is a precondition for quality of life and well-being. Good mental health starts in our workplaces, our schools and our communities. The workplace can be a cause as well as a support for mental health. We need financial support for the Institutions on new Mental Health initiatives. Policy attention for this topic is increasing but still far from being sufficient. Together we can support actions that will lead to a progress in the area of mental health – for those affected, for their families and loved ones and for society as a whole.”



**Sirpa Pietikäinen**  
Member of the European Parliament (EPP, Finland)

“People’s physical and mental wellbeing is a constitutional right that needs to be ensured by the EU. Also the wellbeing of Europe needs people’s mental and physical wellbeing. This is why we need the EU’s mental health agenda to be developed according to these recommendations.“  
#MentalHealthEqualsWealth #EU4BetterWorkLife



**Kira Marie Peter-Hansen**

Member of the European Parliament (Greens/EFA, Denmark)

“Psychosocial occupational safety and health calls from cross-parliamentary attention. Mental health is a fundamental right in our worklife. We have at large still not recognised stress as an occupational disease, even though it affects people a lot, and especially the youth, because of their precarious situation. Workers’ right does not only include a fixed income, work-life-balance or the right to disconnect. It also means a good work environment, where employers take on their responsibility to prevent their workers from stress.”



**Maria Walsh**

Member of the European Parliament (EPP, Ireland)

“Without mental health we cannot have a solid health base. Mental health goes across all borders, all colours; it’s our citizens that are at risk if we don’t get this right. I often say that we can have the best employment policies, the best wage protections, etc. but if the people coming to work do not feel as though they are able to take their whole selves with them to work, or do not feel as though they can be in a positive mental health space in their working environment, then we have a huge problem.”



**Radka Maxová**

Member of the European Parliament (REG, Czechia)

“People’s well-being is a value of itself. Moreover, the link between people’s mental health and economic growth and sustainability is widely acknowledged. Mental health is one of the main causes of workers’ short and long-term work disability, as well as of poor job productivity. At the time of accelerated digitalisation which has a profound effect on the labour market, it is more important than ever to take decisive action as regards workers’ mental health in order to boost the economy and resilience of our society.”



**Mikkel Näkkäljärvi**

Member of the European Committee of the Regions  
Regional Manager of Northern Finland at the Service Union PAM (Finland)

“Mental health issues are the number one reason for sick absences and disability pension in many EU member states and mental health is a big topic especially among young people. It is crucial that the EU, EU member states and regional authorities around Europe start to work more for healthier societies and worklife. Recommendations of EHP’s Committee of Mental Health and Healthy Workforce should be taken into serious consideration.”



**Birgitta Sacrédeus**

Member of the European Committee of the Regions  
Regional Councilor, Region Dalarna

“Health is wealth. More and more EU citizens are on sick leave due to mental illness. Mental illness should therefore be just as acceptable to speak of as physical illness. If we do not treat mental illness with more preventive work, this will also have very large financial consequences for the society besides personal suffering.”



**Stelios Kypourpoulos**

Member of the European Parliament (EPP, Greece)

“As economic globalisation expands, working conditions are intensifying and employees, according to scientific research, are receiving less and less satisfaction from their work. The aim of the European Union should be to design pioneering labour policies “bottom-up” based on the views of the employees on the psychosocial components that they consider the most decisive in the field of work, the contribution of local trade unions in each country, non-governmental organisations, as well as mental health scientists.”



**Tarja Filatov**  
Member of Parliament  
(Finland), Chairman of the  
Parliamentary Advisory Board  
on Mental Health Policy

“The big challenge for working life in Europe in the new decade is to improve mental health and well-being in different work communities: mental health must be actively involved in employment policy. Mental health care needs to be improved for the sake of people, but also for its significant economic dimension. Political decisions determine whether these costs will increase or decrease.”



**Gilles Bloch**  
President of Aviesan,  
Chairman and CEO of Inserm

“Mental health and Brain health are priorities for Aviesan which has always encouraged implementation of additional, voluntary measures to promote mental well-being. Given the important burden on psychiatric disorders, efforts need to be made without delay on promoting medical research in psychiatry, fostering more precise and predictive approach. Knowledge from fundamental research is to contribute to a better understanding of the physio-pathological processes and the appearance of psychiatric disorders and their biological and environmental risk factors. It is also important to help improve our ability to monitor the evolution of these disorders by fostering research on efficient diagnostic, prognostic and stratification biomarkers. Lastly, care need to be led in the direction of more innovative strategies and the involvement of psychotherapeutic and psychosocial approaches. Being committed to such value and after reading the Policy Recommendation entitled ‘Towards a healthy workforce in the EU -Implementing actions for sustainable work life’ which clearly mentioned the necessity of research, Aviesan supports this Recommendation.”



**Martin Jefflén**  
President of Eurocadres  
Council of European  
Professional and Managerial  
Staff

“Most of these very timely recommendations should be followed without delay. COVID-19 worsened an already alarming mental health situation in Europe. To fight the stress pandemic, we urgently need a new EU directive on psychosocial risks at work. Eurocadres started the campaign EndStress.EU for this very reason. Also, as a trade union organisation for managers, we agree with the crucial role of managers and their good training to reduce psychosocial risks, both for managers and other staff.”



**Hilikka Kärkkäinen**  
President of GAMIAN-Europe

“We are delighted to see that psychosocial occupational safety as well as physical and mental wellbeing have been pivotal to the recommendations put forward by the Committee of Mental Health and Healthy Workforce. We strongly agree with the fact that promoting, maintaining and recovering the mental health of the workforce needs to become a priority in the EU. Considering the COVID-19 situation, these recommendations are timely and needed. We are happy to endorse these recommendations and amplify the voice of the next generation of European health leaders rethinking EU health policies.”

# EXECUTIVE SUMMARY

Psychosocial risks and work stress are among the most challenging and pressing European occupational safety and health (OSH) concerns. Work-related stress has emerged as a major challenge not only for employers and employees across Europe, but also for healthcare and health security systems, with roughly half of the EU workforce considering that work-related stress is indeed a challenge they have to face.<sup>1,2</sup> Mental health problems (e.g. burnout, depression, anxiety) impose a heavy toll on individuals, society and the economy, representing a significant share of the EU's burden of disability.<sup>3</sup> Costs for work-related depression alone in the EU are over EUR 600 billion per year<sup>4</sup> – or more than 4% of GDP – while mental health problems increase the corporate costs of employers by several billions per year.<sup>5</sup> This ensuing high cost of work absenteeism along with the growing recognition of the link between human capital and resources and business outcomes demand a targeted effort to improve our limited knowledge around work-related clinical (depression and anxiety disorders) and non-clinical mental health issues (burnout, stress, depressive symptoms) and instruments to manage workers' mental health and well-being. Good planning and the proper involvement of workers in the assessment of psychosocial risks can optimise working conditions through priority preventive measures, thereby creating benefits for workers and employers.<sup>6</sup>

**Promoting, maintaining and recovering the mental health of the workforce needs to become a priority in the EU.**

The mental health of the workforce and the concept of the Economy of Wellbeing<sup>7,8</sup> are two undeniably linked themes. They require the attention of the EU from a political, societal but also economical point of view. The EU needs to encourage and stimulate the engagement of EU citizens in matters and actions related to the understanding of the importance of mental health (bottom-up approach). A better societal understanding will not only allow the EU to promote mental wellbeing, but also will pave the way for

targeted public and private investment, focusing for example in the field of prevention.

Our recommendations aim to highlight the need to focus on the psychosocial occupational safety, health and wellbeing of the workforce by engaging EU citizens in the fight against stigma, promoting tools to foster pan-European collaborations and increasing the impact of existing policies and future recommendations:

- I. The EU and Member States' national and regional governments should include recommendations for the promotion of good mental health and the management of psychosocial risks in all labour and workplace-related policies.**
- II. Policymakers, elected representatives/ government representatives, employers and employees should make better and more frequent use of the collective intelligence of scientific research, NGOs, stakeholder initiatives and engaged citizens in an inclusive approach to ensure solutions towards psychosocially safe and healthy work life.**
- III. Develop an EU quality framework for existing and new digital tools, to guide implementation of psychosocial occupational safety and health risks management.**
- IV. Future interventions and policies need to recognise managers as agents of change in reducing psychosocial risks at work, promoting mentally safe workplaces and creating a culture of openness towards mental health.**

**#MentalHealthEqualsWealth  
#EU4BetterWorklife**

# INTRODUCTION

Exposure to psychosocial hazards and high levels of stress are not only associated with the development of mental illness, such as depression, anxiety and sleep problems, but also linked to a series of non-communicable disease comorbidities like diabetes, cardiovascular and musculoskeletal disease.<sup>9</sup> Even though mental health issues have become the number one reason for sickness absences and disability pension in several EU member states, especially among young people and employees in professions with high social interaction,<sup>10</sup> our understanding of work-related mental comorbidities is extremely limited. The COVID-19 pandemic has further highlighted the need for action; the change of working methods and workload, the increase of unemployment and fear for income as well as the increased ethical burden in health care professions, have aggravated work-related stress and the psychosocial burden of the workforce.

Psychosocial hazards and work-related stress are imposing additional expenditure on the healthcare and health insurance systems of the EU member states, having a detrimental impact not only on the public economy but also on the employment estimates.<sup>11</sup> Nearly 80% of European managers are concerned about problems with stress in their establishment. However, less than 30% of European organisations have procedures in place to deal with psychosocial risks.<sup>12,13</sup> A healthy, stimulating and challenging work environment contributes to the mental health and the wellbeing of its workforce, allowing them to promote its personal development and contributing to the improvement of its quality of life. In parallel, a healthy workforce has a positive impact at an individual, organisational and societal level in building a healthy working culture and a strong economy.<sup>14</sup>

Mental health is wealth. The Committee of Mental Health and Healthy Workforce of European Health Parliament strongly believes that psychosocial occupational safety and health needs to be a priority in the EU. By breaking the stigma around mental

health, increasing openness and knowledge-based risks management, as well as easing access to mental health guidance (including digital tools), the impact of mental health symptoms can be reduced on the level of an individual employee, a work community, an organisation's finances, and society at large. Overall, a psychosocially safe and healthy work environment can increase productivity, engagement, and innovation.

Human capital is the cornerstone of any organisation, country and the EU, and thus it is crucial that the mental wellbeing of the workforce is put first in the list of priorities. We call upon policymakers and representatives of employers and employees to act on psychosocial occupational safety and health risk management. With the four recommendations laid out in this document we propose actions on all necessary levels, aiming towards a sustainable EU psychosocial occupational safety and health agenda and an agenda for a wellbeing workforce to be adopted by EU member states but mainly to be embraced by EU citizens. The mental health and wellbeing of the workforce demands for social welfare policies for a sustainable and healthy EU future.



## **POLICY ENVIRONMENT – THE CURRENT EU MENTAL HEALTH AGENDA FOCUSES ON THE EU MENTAL HEALTH STRATEGY**

In February 2020 GAMIAN-Europe and Mental Health Europe held a joint meeting in the European Parliament, called 'Shaping a future EU Mental Health Strategy: priorities and activities', addressing the urgent need to put in place a comprehensive and proactive EU Mental Health Strategy.<sup>15</sup> However, at this event the European Commission stated that it would not develop an EU Mental Health Strategy but that it will continue best practice sharing and work through CHAFAE.<sup>16</sup> In December 2019 the EPSCO Council agreed on the need to develop and implement an EU Mental Health Strategy.<sup>17</sup> In October 2019 The Finnish Presidency Council Conclusions invited the Commission to propose a Mental Health Strategy, taking into account the cross-sectoral impacts of different policies on mental health, including psychosocial occupational safety and health.<sup>18, 19</sup>

### **The EU Mental Health agenda in 2018 and 2019 – the topic is addressed from different points of view and getting more attention despite the fact that these are recent developments**

In October 2019 Health Commissioner Stella Kyriakides, during her hearing in the European Parliament, underlined her intention to ensure that mental health would get back on the EU agenda, working across the various departments to ensure a consistent and comprehensive approach.<sup>20</sup> During the same month, Jobs and Social Rights Commissioner Nicholas Schmit highlighted, in a hearing in the European Parliament, the importance of focusing on the European Social Pillar of Rights and fair minimum wage.<sup>21, 22</sup> The European Agency for Safety and Health at Work released the Third European Survey of Enterprises on New and Emerging Risks (ESENER 3)<sup>23</sup> in 2019 and the "Healthy workers, thriving companies – a practical guide to wellbeing at work"<sup>24</sup> in 2018. The OECD launched Recommendation of the Council on OECD Legal Instruments Integrated Mental Health, Skills and Work Policy<sup>25</sup> in 2019 and Integrated Mental Health, Skills and Work Policy<sup>26</sup> in 2018.

### **2013-2017 The EU Mental Health agenda pivots on two important subjects – A European Action Plan on Mental Health as well as mental health and work**

The European Commission introduced the EU-Compass for Action on Mental Health and Well-being<sup>27</sup> which in 2017 published a Consensus Paper called Mental Health in the Workplace in Europe.<sup>28</sup> In 2016 the European Commission proposed the European Framework for Action on Mental Health and Wellbeing.<sup>29</sup> That same year GAMIAN-Europe proposed an EU level Action Plan on Mental health.<sup>30</sup> In 2015 WHO Europe launched The European Mental Health Action Plan 2013–2020<sup>31</sup> while the OECD published the OECD Policy Framework From The OECD High-level Policy Forum On Mental Health And Work.<sup>32</sup> The European Agency for Safety and Health at Work published Well-being at work: creating a positive work environment<sup>33</sup> in 2013 along with its summary E-fact 76: Well-being at work: creating a positive work environment.<sup>34</sup> The European Commission supported The Joint Action for Mental Health and Well-being that ran from 2013 to 2016.<sup>35</sup>

### **2008-2012 The beginning of the EU Mental Health agenda – mental health gets a platform in the EU, the MEP Alliance and MH Coalition formed, and the WHO as well as the European Commission address the issue**

The Coalition for Mental Health and Wellbeing in the European Parliament was established in 2012.<sup>36</sup> The European Commission launched MENTAL WELL-BEING: FOR A SMART, INCLUSIVE AND SUSTAINABLE EUROPE (2011).<sup>37</sup> WHO Europe releases Mental health and well-being at the workplace – protection and inclusion in challenging times (2010).<sup>38</sup> The MEP Alliance for Mental Health was established in 2009 as the European Parliament Interest Group on Mental Health, Wellbeing and Brain Disorders.<sup>39</sup> The European Commission launched European Pact for Mental Health and Wellbeing (2008).<sup>40</sup>

# RECOMMENDATIONS

## The EU and Member States' national and regional governments should include recommendations for the promotion of good mental health and the management of psycho-social risks in all labour and workplace-related policies

Mental health problems cost the EU 4.1% of its total GDP in 2015.<sup>41</sup> Preventable situations such as work-related stress and burnout are still a large part of this cost, borne by employers, governments (social security), and society as a whole. Despite the existing EU-level legislation explained above, that provides for minimum requirements and guidelines for Member States in their policies regarding safety in the workplace and employment, these are often overlooked when it comes to mental health and psychosocial risks. Fortunately, this trend is slowly changing. Nevertheless, in most EU countries, mental health policies and practices are mainly related to general health regulations rather than labour and employment.<sup>42</sup> However, one may argue that Member States in general have neither effectively transposed the existing EU legislation into their national legislation, nor have they developed adequate tools or guidelines to effectively support employers, given the worrisome human and economic costs that Europe still carries today as a result of psychosocial risks in the workplace.<sup>43</sup>

In Spain, 2017, the Andalusian Court conceded permanent disability to a factory manager for work-related burnout syndrome. Burnout was henceforth considered a workplace accident.

(Ruling n° 1683/2017, 1st June 2017, Superior Court of Andalucía)

Member States and regional authorities should therefore not only ensure that minimum required standards set by EU regulations are met, but they should also include promotion of good mental health and the management of psychosocial risks in all labour and workplace-related policies. We recommend considering the following:

- › **More advanced benchmarks are needed** for managing psychosocial risks and providing for a positive work environment, considering progress made in several EU member states (e.g. Spain or Finland) and further considering the elements already presented in the proposal to the Council of the EU of a European Mental Health Strategy.
- › **Create a “new normal” in working practices:** The Covid-19 crisis has raised awareness not only of the impact of constraining circumstances on mental health and wellbeing but also of the

Finland has an online platform, called Mental Health Hub, used by every hospital district in the country and open for public. It provides for online mental health assessment, therapy and follow-up, and has been proven very successful in the past 10 years. It is funded by the Helsinki Hospital district and the government.

employers' understanding and acceptance of new ways of remote working without losing productivity. While acknowledging that this cannot be applied to all sectors, all levels of government in collaboration with employer and employee organisations should aim to reform old policies and develop new ones, providing employers with regulations, and practical application guides for resuming work post-COVID while embracing new working norms, like remote working, in a way that accommodates for the needs of most workers. With the increase of teleworking, the Committee of Mental Health and Healthy Workforce of European Health Parliament supports the example of France in 2016 and a legislative initiative by MEP Alex Agius Saliba about the right to digitally disconnect.<sup>44</sup> There is currently no European legal framework directly defining and regulating the right to switch off.<sup>45</sup>

- › **Add psychosocial risks management into EU-legislation:** At present the EU Directive for Occupational Safety and Health is insufficient in the area of psychosocial risks. Within the European labour market regional differences concerning psychosocial occupational safety and health occur, which disrupts equality between European workforce. The Committee of Mental Health and Healthy Workforce calls for a new EU Directive on psychosocial risks at work or an Amendment for psychosocial risks onto the existing framework of EU Occupational Safety and Health legislation. The Committee supports the work of the #EndStress campaign by Eurocadres and ETUC on this matter.<sup>46</sup>



## Policymakers and representatives of employers and employees should make better and more frequent use of the collective intelligence of NGOs, stakeholder initiatives and engaged citizens in an inclusive approach to ensure solutions towards psychosocially safe and healthy work life

The great majority of European citizens are concerned with psychosocial occupational health and safety at different stages of their life: as a young person trying to make the jump from internship to paid employment, as an experienced worker trying to balance family and work, as an older employee who needs to adapt to a changing work environment. Therefore, the concerns and needs of the workforce need to be considered when developing policies or interventions. A general democratisation of the EU and its decision-making practices is required: Governments of EU Member States and the EU should consult scientific and expert committees, including representatives of employers and employees, as well as academic, and non-governmental organisations (NGOs) when initiating change and improving practices.

However, this is a process that would demand first and foremost the engagement of the public. EU citizens need to be educated so that they can understand and embrace the importance of mental health, while in parallel raising their voice when needed. Our understanding of work-related mental health and its impact on the workers' wellbeing, retention, productivity and patient outcomes is extremely limited. Dissemination of the research results of existing and new EU funding schemes,

focusing on the understanding of work and non-work-related mental health should be used to this aim. Moreover, the EU would need to apply more adequate mechanisms to collect citizens' views at EU level, and also incorporate inputs from organisations channelling EU public, including NGOs, patient organisations, labour unions and grassroots initiatives. As a final though not less important note, the EU needs to promote the cooperation and collaboration among the many NGOs and mental-health orientated organisations. Building strong partnerships for mental health promotion at work will not only improve the engagement of the public, but will also decrease the need for unnecessary competition over scarce funding.

Overall, we propose:

- › **Promote the education of EU citizens on mental health:** The EU needs to support research activity on Brain and Mind sciences, promoting the understanding of mental health, and at the same time facilitate the implementation of multilevel interventions in occupational settings, enabling the dissemination of research schemes. Academia and scientific institutions should be in the frontline in promoting the education of the public on the importance of psychosocial occupational safety and the equal value of mental and physical health, thus ensuring the quality of knowledge and acting as a countermeasure against public misinformation.
- › **Initiate and support awareness and de-stigmatisation campaigns:** All actors should join forces to set up various awareness schemes fighting the stigma of mental health issues. Dissemination of research results should be used to promote societal culture in EU-endorsed public science outreach events and workplace seminars, increasing employee awareness. In parallel, those who have experienced occupational mental health issues, who are the “Experts by Experience”, should be empowered to share their insight. Skill-building towards better understanding and management of mental health should be a focus for everyone.<sup>47</sup>

- › **Partnership for occupational mental health:** EU funding should be increasingly provided to cross-sector and multi-stakeholder partnerships, for example those between public and private organisations. The current stakeholder landscape could be improved by a common platform, i.e. [Mentalsundhed.dk](https://www.mentalsundhed.dk) in Denmark, for exchange of knowledge, ideas and best practices, in particular improving the sharing of results, tools and already integrated measures adopted by companies and trade unions. Moreover, the issue of psychosocial occupational safety and health is not yet covered by any of the groups in the DG SANTE's Health Policy Platform: The Committee suggests that a group is created for this topic.



- › **A bottom-up approach:** There should be further development of new legislation and initiatives based on the dissemination of scientific research and the collection of views from mental health NGOs, relevant stakeholders as well as patient organisation initiatives (i.e. European Patients' Forum).<sup>48</sup> The Committee urges the EU to take an active role in empowering citizen activity and use of best practice sharing. EU citizens should be empowered to act on disruptive and novel initiatives on a small scale, allowing the EU to use their findings in the legislative process.

## Develop an EU quality framework for existing and new digital tools, to guide implementation of psychosocial occupational safety and health risk management

More than ever, due to the COVID-19 crisis, the European society and its workforce are dealing with their physical and mental health. Therefore, current digital possibilities enable individuals with access to digital devices the opportunity to improve their mental health with tools like smartphone applications, web-based solutions, and online education. Given the overwhelming range of health care applications (apps) with different purposes, addressing for example symptom relief or health education, individuals face uncertainty concerning quantitative and qualitative criteria regarding product quality.<sup>49, 50</sup> This obstacle may act as a deterrent and thus prevent employers and, for example, occupational insurance institutions from offering use of tools as a company policy for management of psychosocial risks. At the same time, individuals may rely on the guidance of star ranking in app stores, while evidence shows that star ratings are a poor indication for the utility and the usability of an app.<sup>51</sup> For those reasons, mental health apps designed to promote mental well-being, should

be quantitatively and qualitatively labelled to give a more structured and evidence-based advice to the individual and the providing organisation.<sup>52</sup>

While the implementation of effective apps is on a national or individual level, the most effective way to ensure the selection of higher-quality existing apps and to incentivize the development of good new ones would be to start at European level. We recommend considering the following on European level:

- › **European application agency for health-related products:** Like the European Medicine Agency offers independent recommendations concerning medicines in veterinary and human use, a regulatory authority on European level should be implemented to evaluate the efficiency and safety of health-related apps, such as mental health related apps, for prevention, intervention and post-therapeutic settings. To ensure safety and quality of care for the final customer, scientific evaluation of data, standardized procedure of app validation and verification should be conducted. With monitored quality in healthcare apps, organisations and insurance policies are able to recommend new means for the employees to improve their wellbeing.
- › **A quality framework using evidence-based indicators:** Standardising quality criteria would give a quality ranking of effective and evidence-based technical solutions i.e. apps. On a national level this ranking offers healthcare organisations and insurance providers the possibility to recommend and select qualified apps to help individuals in their choice, in order to keep the mental health and related outcomes (especially in society critical situations) at a high level. On a company level this framework helps app developers to focus on specific evidence criteria to derive a high-quality product.
- › **Data privacy and security:** The European Data Protection Board (EDBP) should develop a framework for digital mental health tools and other health-related digital solutions on how data privacy and security should be ensured. There might be stricter regulations applicable to the workplace or national level, in addition to the minimum privacy standards for Europe as outlined by the GDPR. People's privacy and health data need to

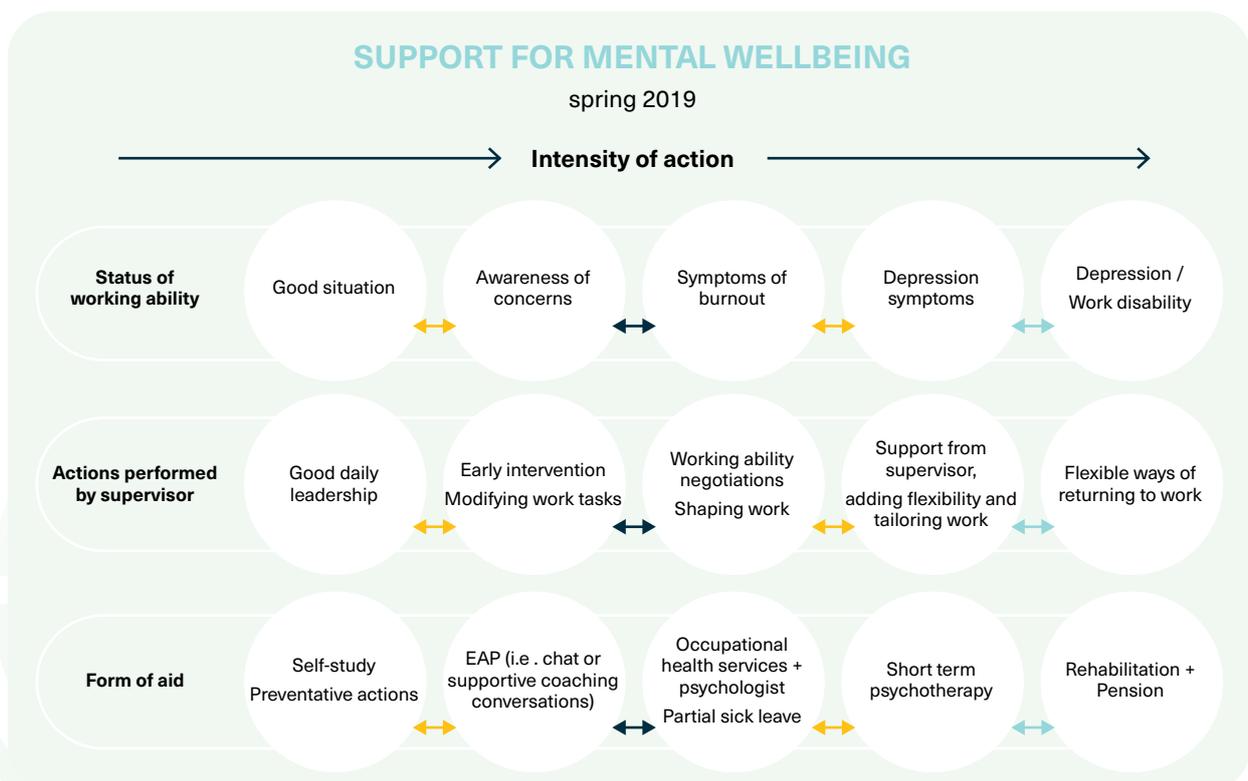
be protected, by clearly indicating in the app store which apps fulfil the necessary data protection requirements.

- › **Joint efforts on effectiveness:** Use of joint efforts and best practice should be strengthened throughout the EU. The use of digital tools for psychosocial occupational safety is also very suitable for such a structure.<sup>53</sup>

Managers are key players in improving the mental health of employees in any organisation, setting the tone of the organisational culture and assuming responsibility for the people they lead. Competent leadership that sets positive examples for the rest of the staff impacts all aspects of working life, including people’s wellbeing, productivity, and overall financial outcomes of the organisation. Not only do managers have a strong impact on the wellbeing of the people they manage, but are also themselves in a position that poses particular challenges to their mental health.

## Future interventions and policies need to recognise managers as agents of change in reducing psychosocial risks at work, promoting mentally safe workplaces and creating a culture of openness towards mental health

Therefore, policies and interventions that are targeted at reducing psychosocial risks at work should recognise the important position of managerial staff and develop strategies to empower them to be positive role models. Not only will such interventions have a high impact, but they can also be achieved at comparably low cost and with a high cost-efficiency.<sup>54</sup> The infographic below shows an example of how the largest private employer in Finland, SOK Corporation,<sup>55</sup> has included support for mental wellbeing of its workforce into HR practice since 2018, by assessing the status of working ability and having a protocol for different intensity of actions in relation to it. The image clearly demonstrates possible steps between work-ability and disability, though





the needs and activities in different organisations may vary. De-stigmatisation and openness towards mental health in the workplace can lead to earlier intervention and decreased impact of the risks for individuals and the organisation, as well as society as a whole. Psychosocial occupational safety and health risk management contribute to sustainable work life.

While including the role of management into policies would be desirable, the most immediate difference can be made on organisational level, on which we recommend considering the following:

- › Reducing psychosocial risks at work by training managers: Managers should be provided with training on occupational psychological risk factors and symptoms of mental health issues to be able to recognize situations when help or additional conversation might be needed. Moreover, they should be made aware of methods and pathways for seeking help, e.g. services provided by the organisation or through the local healthcare system, to be able to offer guidance.
- › Promoting mentally safe workplaces and creating a culture of openness towards mental health through managers leading by example: Managers should pioneer the development of a safe and open work culture that allows for conversations about mental health, e.g. by encouraging staff members who struggle with mental health to seek guidance and take sick leave, if needed, promoting the right to disconnect and making mental health part of staff dialogues, if appropriate. Furthermore, managers should be empowered to maintain and promote their own mental health.

- › Holding managers accountable: A manager's ability to create a mentally safe workplace for their team should be part of their work objectives and performance review. Assessment of psychosocial risks should be made a standardized part of any workplace assessment.
- › Sharing of tools and practices to address and assess psychosocial risks in the workplace: The EHP Committee of Mental Health and Healthy Workforce supports the CHRODISplus Joint Action toolbox and working packages for psychosocial risks management in the workplace. Though the CHRODISplus Joint Action focuses on the needs of people with chronic diseases, its approach toward psychosocial risks is inclusive, regardless of state of health or pre-existing medical conditions. The toolbox is estimated to be published before the end of 2020.<sup>56</sup>

### Good examples of mental health leadership: Winners of the Healthy Workplaces Good Practices Awards 2014- 2015

- › Deutsche Post DHL Group, Germany, considers the commitment of managers to mental health essential and developed a "Leadership and Mental Health" web-based training programme for managerial staff.
- › Lån & Spar Bank, Denmark, trained managers to be certified coaches for both private and work lives, and also provides employees access to psychological counselling.

# CONCLUSIONS

**What will the working life of tomorrow be like?**

Futurist Perttu Pölönen, honoured among 35 Innovators Under 35 in Europe by MIT Tech Review, has stated that to counterbalance technological advancement in the future, human aspects and multidisciplinary thinking will be fundamental.<sup>57</sup>

There are no easy solutions to promote the mental health of the workforce. With this Policy Recommendation, we propose a call to action for both policymakers as well as organisational management to take care of the most important capital, the workforce. We also want to highlight the need for more collaboration on the issue, and sharing of good practices. The cost of Mental Health issues is estimated at 4% of EU GDP. By taking steps towards a more psychosocially safe and healthy working life, the cost can be reduced – prevention and fast intervention saves money.

**Will productivity and engagement increase with a healthier workforce? You need to ask yourself, what kind of employment would you rather engage with – one where you feel safe and appreciated as an employee, or the opposite? Would you rather work on a construction site with a helmet or without one? Fear is the best way to decrease creativity and innovation.**

The working life of tomorrow is about human resources. We, the Committee members with 35+ years of employment ahead of us, urge for action towards better psychosocial occupational safety and health risks management in the EU.



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