



**A SHARED VISION FOR THE
FUTURE OF HEALTH IN EUROPE**
Paving the way in 2019 and beyond

RECOMMENDATIONS IN FULL



► Invest in and support the implementation of evidence-based programmes for prevention

With better prevention, hundreds of thousands of lives can be saved every year in the EU and EU citizens can live their lives in good health. Prevention, including primary prevention, screening and vaccination, as well as investing in the prevention of chronic disease progression, will have the advantage of reducing both health- and socio-economic costs.

The EU should create a framework to help Member States, regions and responsible authorities generate greater impact from health promotion and disease prevention, including through citizen and patient empowerment. Helping citizens take a more active role in caring for their health and wellbeing

is key. Developments in population health management concepts, complemented by the impact of technological developments such as diagnostics, digital tools and apps offer novel opportunities for more personalised approaches to enabling citizens to remain healthy. Primary care needs to evolve to respond to, or indeed drive, this new relationship with citizens. Prevention could also become more effective by improvements in using genomics and other data to identify risk groups and tailor preventive measures that will further advance the impact of interventions. It will continue to be important to ensure that existing EU health policy recommendations, such as alignment of screening and vaccination, are applied at national and local levels, with proper investments schemes.

► Support the implementation of standardised measurements of health outcomes and healthy life years

The EU should establish and help implement, together with patient organisations and other healthcare stakeholders, standards for measuring patient-relevant health outcomes across diseases and conditions, as well as to measure healthy lifespan on a population level.

Standardised data on patient-relevant outcomes will enable comparisons and benchmarking across providers, regions and Member States, and is a key component for developing outcomes- and value-based systems. This includes the systematic capturing of key Patient Reported Outcomes Measurement (PROMs) related to the entire patient journey for different conditions and for multiple conditions, including the functionality, quality of life and psycho-social context as well as Patient Reported Experience Measures (PREMs). By agreeing on common standards, and by having the EU institutions supporting their implementation, health outcomes and progress can be tracked in a more frequent and robust way than

is the case today. This work should build, as appropriate, on the Organisation for Economic Co-operation and Development (OECD) Patient Reported Indicator Survey (PaRIS) project.

Complementing the measurement of disease-specific outcomes, an instrument to measure healthy lifespan of citizens should be established. Healthy lifespan is the most important system-level outcome measure that is not currently being routinely measured. Healthy lifespan represents the age when people first enter a period of poor health in their lives. A highly innovative, 'first-of-its-kind' programme to measure healthy lifespan should be established across all Member States to baseline and benchmark the current position, complemented by annual data reviews. This will allow health systems to proactively identify their currently healthy populations, and provide insight into the local reasons why people are first entering a period of significant poor health in their lives.

► Identify and spread best practices in medical practice and care pathways

Public health policymakers, healthcare managers, providers and patients across Europe should be able to make decisions based on the best available evidence. Comparative outcomes data will help determine which medical practices, care pathways and providers have demonstrated the best results.

Using patient-relevant health outcomes data for comparison and analysing variation will help identify what caused these outcomes so that good practices can be identified and shared,

and guide investments towards those that bring most value to patients and health systems. Today, recent and useful data are often limited or even absent. Once high quality data allow to identify good practices, including medical pathways, prevention and integrated care models, these practices should be described and disseminated to facilitate uptake throughout health and social care systems. The European Commission should fund pilot projects in areas of high health and social care added value, and as such determine the best approach.

► Strengthen work on monitoring and assessing the performance of health and social care systems

The EU should help Member States to analyse the effectiveness and functioning of the health and social care systems – identifying opportunities for disinvesting in low-value interventions and highlighting high-value actions worthy of further investment – and recommend appropriate reform measures.

Building on work carried out by the European Observatory on Health Systems and Policies and the Expert Group on Health Systems Performance Assessment (HSPA), the EU should as

one of its key mandates in health policy continuously analyse the efficiency and effectiveness of EU health and social care systems, including by identifying inefficient and low-value care. The work should build on the analysis of health outcome variation, performed by our proposed European Health Data Institute, and the assessments as well as comparable data should be published in an expanded EU State of Health report and used to guide recommendations to Member States, including in the context of the European Semester, and support for transforming healthcare and capacity building from EU financial instruments.

► Support health system reform and capacity building

The EU should continue to assist in co-financing health system capacity building through relevant EU funding instruments, in line with European Semester recommendations.

In the context of the Multiannual Financial Framework for 2021-2027, relevant funding instruments, such as, the European Social Fund+ (ESF+) and the European Regional Development Fund (ERDF), should contribute to transforming

and modernising health and social care systems, including through integration of care, health informatics, investments in health information and models for prevention and disease interception. The EU should provide Member States and regions with the relevant expertise to guide investments in health systems in an evidence-based way, informed by the comparative data, learnings and assessments carried out according to the previous recommendations.

► Establish a Forum for Better Access to Health Innovation

A multi-stakeholder forum on better access to health innovation should be created to discuss barriers and solutions to further innovation.

The time frame within which some innovative technologies reach the patient can be very long. For pharmaceutical products, the average length of national accessibility of new treatments after European approval is almost 400 days, and even longer for most cancer medicines. Initiatives that further access to and affordability of innovation should be encouraged. A multi-stakeholder Forum on Better Access to Health Innovation

should be facilitated by the European Commission involving all stakeholders – including national and regional authorities, patients and civil society, healthcare professionals and industry – which would discuss drivers and barriers to access innovation, including economic, budgetary, organisational and regulatory. In addition to innovative technologies, the Forum should also discuss the introduction of related healthcare services and care pathways, and how to address barriers and inefficiencies created by fragmented organisational and financial models. The work should be based on solid data from horizon scanning and monitoring of access to innovation.

► Ensure better access for patients to cross-border healthcare

Cross-border healthcare should become a reality by allowing patients to get access to health services in other Member States, including diagnosis and clinical trials, based on the principle of easiest, closest, best and fastest access.

The current EU cross-border healthcare directive was a good first step in improving patients' rights to cross-border healthcare, but still contains several constraints and possibilities

for national insurance systems in blocking cross-border access. Especially in border regions stronger support from the European Commission through cohesion policy is absolutely needed to address the challenges in the health sector. The current implementation of the directive should be carefully analysed with a view to a strengthening of the legal framework, including in terms of providing transparent information to support patient choice.

► Support evidence-based care at scale by building on the European Reference Networks and supporting European registries

The European Reference Networks (ERNs) have been a success which should be sustained and expanded, and the EU should support sustainable collaboration between European registries in other disease areas.

Today, the European Reference Networks (ERNs) represent collaborations of over 900 associated hospitals working on 24 rare and complex diseases, pooling knowledge across Europe to improve outcomes for patients. However, areas beyond rare diseases would benefit from a more pan-European approach to supporting care, including guideline development, consultation

and data collection. The success of this collaboration is a good basis to further expand and deepen the ERNs, including through more sustainable funding and integration into standard care pathways, and to support European level disease registries, or alliances of national registries with common core data sets, beyond rare diseases. ERNs and European scale registries constitute a unique opportunity for health research, and clear EU level rules for collaboration with academic and private researchers and clinical trial sponsors should therefore be established.

► Establish a European health education programme for healthcare professionals and citizens

In order to support the European health and social care workforce, better integrate basic research with clinical practice and empower clinicians and patients in the use of new digital health tools, there is a need for a pan-European approach to education and skills development.

The transition to new models of healthcare requires new skills and continuous professional development of the health and social care workforce, but also literacy for citizens and patients in using new digital health tools. The focus of a new European health education programme should be to:

Promote and support frontline initiatives boosting good cooperation at European level exploring the appropriate composition and availability for a sufficient, motivated and highly qualified health and social care workforce, improve the access to continuous professional development, contributing to minimise the gaps between the needs and the supply of health workforce, and guide Member States in scaling-up innovative workforce composition models for integrated, patient-centred care.

b) Establish special training programmes that connect basic researchers with clinical scientists. There is an urgent need for a better integration of complex processes, and the purpose would therefore be to train the next generation of research-oriented clinicians and clinically-oriented researchers. A greater degree of coordination and harmonisation of 'clinician-scientist' training programmes across Europe are needed to do justice to the increasingly international nature of research and clinical practice.

c) Empower clinicians and citizens in using digital tools. In order to realise the benefits of digital and data, everyone needs a level of basic understanding about digital technologies including wearables, apps and medical devices. Several countries are already developing digital academies for clinicians, but the need for such education is far wider covering also patients and citizens. The information, skills and tools which need to be developed are similar across Member States, and the opportunity to create and co-create content and tools that can be used across Member States is substantial.

► Facilitate multi-stakeholder partnerships with regions and cities

Fostering an environment of cooperation with local and regional stakeholders would help to further tackle the health inequalities that persist in Europe.

When defining health policies at EU level, there should be more coherence at the European, national and regional levels. More cooperation at national and regional levels regarding treatment and prevention is needed. In order to achieve this, organisational and financial coherence is paramount. Regions and cities are close to the citizens and therefore best placed to understand their health needs, challenges and the potential workable solutions. Examples such as the European Innovation Partnership on Active and Healthy Ageing (EIP AHA) showed the added value of mobilising a variety of stakeholders across

the value chain, under the European Commission guidance, focusing on a set of shared priorities. The principles and the process of this experience should be replicated also in the future and used as a tool to reinforce the dialogue at local, regional and EU levels. With 6,000 health-related projects financed through the European Structural and Investment Funds (ESIF), cohesion policy showed its crucial contribution in supporting social and economic convergence around Europe. Moreover, the smart specialisation strategies represent an important instrument for coordinating different policies and funds at local level and should be further leveraged. For this reason, the cohesion policy should be allocated sufficient resources in the future programming period, as it represents a long-term investment policy for all regions and cities in Europe.

► **The European Commission should have a Vice-President for health to ensure effective coordination and leadership at high level**

Health and health equity should be considered in all European, national, regional policies and actions. The European Commission should have the tools and governance in place, including at high level, for ensuring a health perspective in all policies. The role of a Vice-President for Health in the new European Commission should be established.

Health inequalities are usually influenced by the interaction of multiple factors also outside the healthcare systems, such as socio-economic differences, education levels, living conditions, lifestyle choices and environmental factors like exposure to poor air quality and hazardous substances. Member States and regions should utilise the full range of entry

points, different strategies and tools to embed and promote Health in All Policies (HiAP) as a method for facilitating an integrated and networked approach to decision-making and governance arrangements. A wide range of HiAP experiences across the globe can be disseminated to aid implementation, such as the importance of leadership, dedicated human and financial resources, partnership and stakeholder management, accountability and evidence in fostering HiAP. The European Commission should have the tools and governance in place, including at high level, for ensuring a health perspective in all policies. The role of a Vice-President for Health in the new European Commission should be established.

► **Implement knowledge transfer and twinning programmes to implement integrated, person-centred care throughout Europe**

The success of the implementation and upscaling of integrated, person-centred care strongly depends on how it is designed to fit the local context and needs. There is a need to support long-term investments in knowledge transfer and twinning programmes to help regions and Members States to adapt along a very complex journey of change for integrated care.

Knowledge transfer has been greatly recognised as an effective enabler to access existing evidence and learning on integrated care. However, effective knowledge management requires dedicated ongoing support and infrastructure that will address the needs of health and social care authorities and facilitates

access to resources and expertise that will improve their capacity to implement integrated care. As such, there is a need to support long-term investments in knowledge transfer and twinning programmes and coaching activities and other learning events with health authorities, stakeholders, medical staff, in order to help regions and Members States to adapt along a very complex journey of change for integrated care. Among these long-term investments, innovative projects in areas such as Electronic Health Records (EHR), case management, person-centred disease management, patient empowerment and involvement, tele doctors, ePrescription, bundled payments and coaching will be critical.

► **Support people with chronic conditions in the workplace**

Integrating people with chronic physical and mental health conditions in employment is socio-economically beneficial, as well as ensuring the return to work after a severe illness. Better coordination among EU health, cohesion, employment and social policies/programmes is essential, as well as sharing knowledge and best practices – including models already adopted by employers.

While some people with chronic conditions cannot continue their professional activity due to their health state, many continue working or wish to do so, while for others working is a necessity. With adequate support, those who wish to, can work, resulting in a hugely improved quality of life that minimises the negative financial impact of chronic illness,

risk of social exclusion, poverty and positively contributes to mental health. Best practices to retain and reintegrate people with chronic – but also acute – conditions are widespread, as are funding initiatives and policy tools such as the European Pillar of Social Rights, the European Social Fund (ESF) and the European Semester process. However, the EU and its Member States should push for better implementation – as well as acknowledge that accurate, early diagnosis and access to appropriate treatment/management are necessary to enable those with chronic conditions to avail of these supports. This will require cooperation across European Commission Directorate-Generals (DGs) and a less siloed approach to health, research, employment and social affairs, finance, the regions and beyond.

► Establish a Steering Board for Health to ensure optimal coordination of research activities

A Steering Board for Health should coordinate health programmes under Horizon Europe, guide applicants and create greater visibility for European health research programmes. The EU budget for health research should be increased and ring-fenced.

There should be a better coordination of national and European funding mechanisms to ensure complementarity of the funding programmes. The European Commission should therefore establish a Steering Board for Health that shall focus on the following key issues: sustainability, accessibility and synergy between health research programmes; scientific advice and recommendations; value oriented health research, and better health solutions and reduction of health inequalities. Such a Steering Board for Health, composed of stakeholders from biomedical research and innovation, other relevant sectors of research and industry and with strong participation of patient representatives and society, is of specific value for coordinating health programmes and health missions under Horizon Europe.

The Steering Board would also help increase the visibility and effectiveness of European health research through integrated and coordinated communication, and increase the clarity and transparency through establishing a 'blueprint' of existing funding mechanisms (such as Horizon Europe, European Social Fund, Digital Europe and national funds) and a 'One Stop Shop' for health research.

The Steering Board for Health should be considered as a pilot and a first step towards the establishment of a European Council for Health Research. It should promote deeper and longer-term collaborative and transnational initiatives that address the current gaps in the innovation cycle and strengthen cross-fertilisation and collaboration across all relevant disciplines as well as citizen participation. It should further provide strategic advice on the steering of European health research to policymakers, and address the partially fragmented responsibilities for science and research at the EU level.

► Increase and ring-fence the budget for health research

An increased EU budget for health research, as well as an increase in national funding for research is required in order to tackle the major health challenges Europe is facing. Sound measures are a must in order to ensure that outstanding basic research leads to the necessary translational impact in the real-world setting and improves patients' lives.

Funding excellence research in Europe to tackle societal challenges and address unmet medical needs requires dedicated support. The EU manages only one-tenth of the public research investment, but is the major funder of impactful, collaborative and transnational research. Horizon Europe proposed budgets

do not make full use of the research potentials as well as requirements within Europe. EU budget for health research should be ring-fenced and 25% of the Horizon Europe budget should be dedicated to biomedical and health-related research. Collaborative research is needed to foster knowledge transfer, entrepreneurship and partnerships between academia, industry and civil society, and to maintain Europe competitiveness. An increase in EU funding should go hand in hand with strong national funding. Horizon Europe should provide incentives that Member States increase gradually their national funding for basic and translational research.

► Further the collaboration of public and private sectors in health research

Set up a cross-sectorial health research Public Private Partnership.

The ability to build unique institutionalised partnerships that contribute to breaking silos between industries, public and private sectors, research and healthcare, will increase Europe's attractiveness in the global collaborative research landscape. Complex challenges of ageing societies also call for integrated care solutions and these require much smarter integration of products, services and technologies and much deeper

collaboration between public and private health and health research stakeholders. Building on 10 years of successful experience of European Partnerships such as the Innovative Medicines Initiative (IMI) and the Electronic Components and Systems for European Leadership (ECSEL), it is essential that the public private partnership under Horizon Europe further enhances the collaborative research culture that balances public health and health industries competitiveness when new development, evaluation and deployment pathways for novel health and healthcare solutions are designed.

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► Assessment of funded health research programmes

Research on research is needed. A mechanism should be in place able to assess the funded health research programmes, and oversee if the outcomes have a translational impact in the real-world setting across the larger innovation ecosystem.

The percentage of medicines and innovations developed outside Europe is high in the light of the quality and quantity of European health research. Clearly there are gaps in the innovation cycle. Outstanding basic research is not always followed by the necessary translational impact in the real-world setting, and very often it does not have an impact on patients'

lives. The re-search outcomes do not live up the expectations of competitive markets, and they are not sufficiently translated into medical practices. Investment often requires taking a step into the un-known to bring about new discoveries. A mechanism should be in place able to monitor and critically assess the funded health research programmes and external factors relevant for the translation of research outputs into real-world innovation, and oversee if the outcomes meet the patients' needs and the current societal challenges. This must address the missing link between regulatory trials and healthcare systems.

► Establish a European Health Data Institute to produce a range of health data to inform the work of policymakers, researchers, industry and healthcare providers

Member States, regions, payers, insurance companies and data donors should make available national data sets to facilitate the European Institute. The information produced by the Institute could help stimulate a European market in health informatics, research and analytics.

Member States could mandate health data holders to flow pseudonymised data to a European Health Data Institute, building on the efforts to set up a European Research Infrastructure Consortium for health information. This would use common data specifications, agreed among Member States, and would rely on existing clinical diagnosis and procedure codes, which are currently collected. The overall value of the European Health Data Institute would be the cross-sector aspects (super computing, data as a service for the single digital market, empowering both academic and commercial research and the development/enhancement of a data scientist capability). This would promote the creation of jobs and growth in Gross Domestic Product (GDP) in health, life sciences, technology and social care.

A European Digital Platform should be created to facilitate accountability for health data use and consent management

A European Digital Platform could provide a framework for the governance of personal health data, enabling patients to

express their choices regarding the use of their health data for health and care research.

There are many patients who want to consent to ethical research and innovation, but they want to know that their data is used for legitimate purposes and that it is adequately protected. Public and private researchers could go to one place to obtain patient data that would allow regions and Member States to release the consented records. The European Commission should work at the political level to secure Member State support for the Platform. The Digital Platform would allow citizens to exercise choice over the use of their data consistent with wider societal needs, manage withdrawal of consent and provide a platform for informing individual citizens about the use of the data. Citizens could choose different levels of access to their data and information requirements and specify and in real time revise their privacy choices. This would create a fast and efficient system for managing accountability to patients, create European Health Big Data access to allow research and the development of innovation for products and services, put citizens in charge of their data, enhancing compliance with the General Data Protection Regulation (GDPR) and strengthening the European Digital Single Market. This initiative should build on the experience of the Innovative Medicines Initiative (IMI) projects and EU initiatives such as the European Reference Networks (ERNs) and the Science Cloud.

► Ensure eHealth interoperability across the continuum of care

EU policymakers, Ministries of Health, regional health authorities and sickness funds need to develop and implement eHealth strategies, guidelines and action plans and provide guidance on interoperability.

Digital health services will play a critical role in the delivery of integrated care. These include Electronic Health Records (EHR), information sharing and care team collaboration tools, personal connected services and tools for citizens, risk stratification as well as decision support systems. However, if services are to genuinely support integrated care models, they must be truly interoperable. The slow deployment of interoperable digital health solutions across Europe remain a barrier for scaling-up integrated care. At the same time, the uptake of connected health and internet based technologies within the health,

social and wellness sectors is increasing rapidly. This may increase the risk of fragmentation at a time when we need more interoperability. In this context, Member States need to reinforce their strategies and where appropriate to adapt their legislation to ensure that citizens have secured access to their health data electronically and can use those data, including across borders in accordance with data protection rules. Member States need to adopt at national and regional level the use of state-of-art standards and technical specifications in their public procurements, to promote cross-border technical and semantic interoperability of EHR systems operating in the EU. The European Commission needs to support Member States and regions in the development and implementation measures to monitor the cross-border interoperability of EHR systems.



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