



# EUROHEALTH

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European Health Forum Gastein 2020



## ➤ Dancing with elephants: New partnerships for health, democracy, business

- The European health workforce
- A wellbeing economy agenda
- The advisors' dilemma
- Realising the EU Pharmaceutical Strategy
- Reducing inequalities in cancer prevention and care
- Fighting health infodemics
- The health democracy deficit and COVID-19
- Perspectives on the European Health Union
- Priorities of Young Gasteiners

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## EUROHEALTH

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## Dancing with elephants – New partnerships for health, democracy, business

Early in 2020, the European Health Forum Gastein (EHFG) team and advisory bodies invited the health community to “join the dancefloor” at the three-day physical conference in the beautiful Gastein Valley in autumn, as usual.

The proposed theme focused on questions regarding if, when, and how to rethink partnerships with those big players that health usually shies away from, or even demonises, in a productive and open way. And how to bring fresh air and momentum into existing partnerships, striving to continuously improve multisectoral collaboration for better health for all. Little did we know back then that nothing would be “business as usual”, and that the dancefloor would be a digital one, dominated by an ominous dance partner – COVID-19.

While 2020 was a challenging year for everyone, it continues to be encouraging that the health community seems determined not to let this crisis pass without harnessing its momentum. Rather than just bemoaning the shortcomings of the initial European Union (EU) reaction to the pandemic as well as the overall lack of international coordination of crisis responses, there has been a real push for thinking about how to make things better in the future. Most remarkably, calls for a strong European Health Union have mushroomed in several settings this year and this was also the topic of the EHFG 2020 Closing Plenary. How can we realise a greater role for the EU in health in a way that retains national sovereignty in health policymaking? Is it better to have stewardship of existing tools, new instruments, even a treaty change – or a mixture of them all? At the EHFG 2020, we saw one common thread running through all our sessions: how COVID-19 has painfully aggravated the shortcomings of our health systems and highlighted those areas in the direst need of sustainable change. Against this backdrop, we invite you to accompany us on a short journey through some of the themes discussed at the digital Gastein Forum this year, spanning our 2020 topic tracks: resilient systems, from data to decisions, and empowerment and agency.

The recent collaboration with one of our more frequent dancing partners, namely the pharmaceutical industry, has proven, in an impressive manner, how much can be achieved in very little time. The development

and joint work on securing the production of several COVID-19 vaccine candidates could set a precedent for other areas, such as Antimicrobial Resistance – and the new pharmaceutical strategy for the EU, explored in the article by Cogan and Nolan in this issue, is a first promising step in that direction. Another topic discussed at the EHFG 2020 and considered by Heiss in this *Eurohealth* is the opportunities and threats of digitalisation and data: how do we counteract the ongoing “infodemic” and provide citizens with the tools needed for navigating an information environment in which anyone can contribute, without proper fact-checking mechanisms? How can digitalisation pave the way towards more equitable and integrated health care systems? Could the pandemic be an epiphany that finally forces us to confront the necessity of data standardisation and data sharing, and push us to truly mobilise the resources needed to gain some ground on this matter? And how can we learn from private industry in the field, in order to engage in partnerships at eye level and harness the untapped potential that may spring from them?

One thing is for sure: we are at a crossroads in history, with only an endless list of open questions to guide us. Let us take all the right turns, together. We hope you enjoy reading this 8th Gastein edition of *Eurohealth*!



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# THE EUROPEAN HEALTH WORKFORCE: CLOSING THE GAPS

By: Martin McKee

**Summary:** Europe may be united politically, but it is divided by health. 30 years after the physical borders between East and West came down, the health of those in central Europe still lags far behind that of their western neighbours yet their health services continue to suffer from underinvestment. The gap is particularly large for the health workforce. The COVID pandemic has shone a light on these long-standing inequalities, but as Europe moves forward into a post-pandemic period, it has an opportunity to address them. This pandemic will not be the last. If Europe is to be prepared for future threats, it must begin the process of creating a European Health Union, in which a strong, resilient, and equitable health workforce will play a major role.

**Keywords:** *Inequalities, Health Workforce, Preparedness, European Health Union*

## A divided Europe

Over 30 years after the fall of the Berlin Wall, Europe remains divided. Not by walls and fences, but by health (see Figure 1). The Global Burden of Disease (GBD) project reports a death rate, in 2019, of 1,201 per 100,000 people in the countries of central Europe (which includes those in the Balkans) that is 22% higher than the figure of 979 in western Europe (the European Economic Area plus the United Kingdom).<sup>1</sup> Measured in Disability Adjusted Life Years, the difference is similar, at 35,488 compared to 29,075 per 100,000. Yet, in a clear demonstration of the Inverse Care Law, it is in central Europe that health services are weakest. The Health Access and Quality Index, developed within the GBD project, captures deaths that should not occur in the presence of timely and effective care.<sup>2</sup> With Iceland, Norway, the Netherlands, and Luxembourg topping

the list worldwide, it is clear that western Europe is performing well. Slovenia comes in at 21st and the Czech Republic comes in at 28th, but their neighbours fare considerably worse, with Poland in 39th position and Hungary in 40th.

There are many reasons for this, and among the most important is the underinvestment in health workers. The opening of borders within Europe has brought many benefits for health services, opening up the market for modern equipment and pharmaceuticals, promoting the exchange of knowledge on evidence-based practice, and providing structural funds for health facilities. However, it also created the conditions for large-scale migration of health workers, seeking better working conditions in western European countries. This was exacerbated by the historical underinvestment in training in some

> #EHFG2020 – Session link:

[https://www.youtube.com/watch?v=VZL\\_U5PK\\_zY](https://www.youtube.com/watch?v=VZL_U5PK_zY)

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western countries, for example the United Kingdom, which had long depended on recruitment from its former colonies.

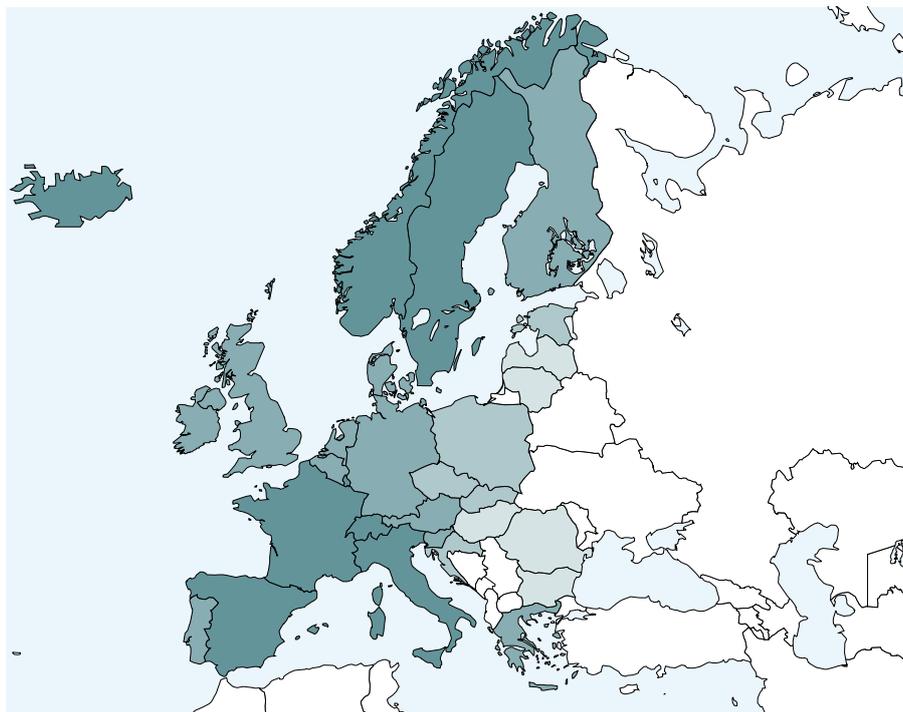
This European health divide was the subject of a panel at the 2020 European Health Forum Gastein chaired by Alex Soros, Deputy Chair of the Open Society Foundations and Vytenis Andriukaitis, former European Union Health Commissioner and Special Envoy for the European Region of the World Health Organization. The other participants were Corinne Hinlopen, Global Health Policy Researcher at Wemos, Salija Ljatif-Petrushovska, Director of the Specialized Hospital for Geriatric and Palliative Medicine in Skopje, and Martin McKee, from the London School of Hygiene & Tropical Medicine and European Observatory on Health Systems and Policies.

### COVID shines a light on longstanding problems

The panel discussed how the COVID pandemic had shone a light on these problems, as health systems across Europe struggled in the face of rising rates of infection. Even those countries that are, in relative terms, well supplied with health workers, health providers struggled in the face of rapidly rising need for care, including many of their own staff who faced daily risks on the front line of the response. As Alex Soros said, “The epidemic affected not only Europe’s most vulnerable patients, but also its most vulnerable workers – including health workers on the front lines, many of them migrants who had left behind failing health systems in their home countries”. Vytenis Andriukaitis added “Europe had witnessed market and state failures to regulate labour markets in the health sector. It’s doable to find win-win solutions for countries donors and countries recipients of health professionals”.

In the initial months of the pandemic, the countries of central Europe were relatively spared. Unlike in some of their western neighbours, they implemented measures to reduce the spread of transmission early. Yet this initial success may have given rise to a degree of complacency and as summer approached, they looked at how they

**Figure 1: Life expectancy at birth (2018 or nearest year)**



Source: WHO

■ <77 ■ 77–80 ■ 80–82 ■ 82–84

might return to a semblance of normality. While some remained cautious, others moved quickly. The Czech Republic held a ‘Goodbye to Coronavirus’ celebration in early July, with tragic consequences as cases began to rise, to reach some of the highest rates in Europe by October.

The pandemic also shed light on another weakness. In the initial panic, Europe’s governments pursued their own interests, competing on global markets for personal protective equipment, tests, and other supplies<sup>2</sup> but also for health and care workers.<sup>3</sup> The pan-European mechanisms that had been created in response to earlier disease threats, such as joint procurement, took far too long to begin. There was some collaboration. Some countries, such as Germany, accepted patients from their struggling neighbours. But in almost all respects, they pursued their own policies, closing borders that had been open since the Schengen Agreement, and creating confusion along increasingly integrated border communities, with different rules on either side of the frontiers. It was only after several months that the European Union developed a concerted roadmap to exit the initial restrictions.<sup>4</sup>

Of course, these differences created an opportunity for researchers. By setting up what were, essentially, natural experiments in which different policies were adopted at different times, it created a situation which might help to determine what policies work in what circumstances. Early in the pandemic differences in mandates on wearing of face coverings in German cities had provided valuable evidence on their effectiveness in reducing transmission.<sup>5</sup> Yet these opportunities were difficult to exploit as the data collected in different jurisdictions varied and, in many cases, simply did not exist. There were substantial differences in definitions, such as of a COVID-related death, and in data collection, such as the intensity of testing. It soon became clear that excess all-cause mortality was one of the best measures of the effectiveness of responses and these data were available in the EuroMoMo project, but for only about two-thirds of Member States.<sup>6</sup>

## What can be done?

Returning to the main theme of the session, what can be done to address the imbalance of health workers in Europe? First, it is essential to improve the working conditions of health workers, and not just their incomes. Improvements should come in their working conditions as well as opportunities for developing their skills and responsibilities. Salija Ljatif-Petrushovska described graphically the challenges faced by those working in a country like North Macedonia.

“creating mechanisms to support health professionals to exchange ideas

In some countries, promotion depends on nepotism rather than expertise, creating a major disincentive for professional development and driving ambitious young health workers to look abroad. A particular challenge is the difference among countries in the status of nurses.

In many European countries it is necessary to ensure that the health workers that do exist are doing what they should, and not be doing what they should not. A recent report from the European Commission's Expert Panel on Investing in Health explored the scope for task shifting.<sup>9</sup> Often seen as a way of delegating tasks to lower skilled and lower paid workers, the report painted a much more complex picture. Tasks should be distributed among and between different types of health workers, patients and their carers, and increasingly, machines. However, for this to happen, ingrained and restrictive practices must be challenged. In many parts of central Europe, the challenge is exacerbated by the persistence of informal payments that create serious barriers to change.<sup>10</sup> Why should a senior doctor ask someone else to do something if they lose income as a result? The pandemic has already brought about changes that would until recently have been thought impossible, such as the

massive growth of online consultations<sup>10</sup> although, as Corinne Hinlopen noted, this needs to be managed carefully to avoid a “digital divide”.<sup>11</sup> Yet the direction of travel is clear. We will see a much greater role for digital health. The panellists were emphatic. Countries in western Europe are facing enormous shortages of health workers, especially nurses, in the coming years and change cannot be delayed.

Taken together, the weaknesses in many health systems in Europe and the failure to work together to address them, have led to calls to “build back better”, offering many practical suggestions for the European Union. These included creating mechanisms to support health professionals to exchange ideas on innovations in models of care, strengthening the voice of civil society and particularly those speaking out for vulnerable communities, and living up to the commitment to pursue Health in All Policies.<sup>12</sup> But the panellists were unanimous that more was needed, supporting the idea of a European Health Union as set out by Commission President Ursula von der Leyen when she told the European Parliament that now is the time to “build a stronger European Health Union”<sup>13</sup> and in a recently launched Manifesto for a European Health Union.<sup>14</sup>

As Corinne Hinlopen said, “now is our moment”. In this she echoed the words of an earlier citizen of Europe, Primo Levi, who had first hand experience of divisions in Europe and asked, “if not now, when?”<sup>15</sup>

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# A WELLBEING ECONOMY AGENDA TO HELP SHAPE THE POST- CORONAVIRUS ECONOMY

By: Katherine Trebeck

## OPINION PIECE

**Summary:** COVID-19 revealed that enormous shifts in policy are possible. In many European countries, the cleavages in labour markets laid bare by COVID-19 illuminate an economy that generates insecurity and despair; an economy that does not account for nature; is blind to distribution; and which puts measures of progress such as Gross Domestic Product (GDP) to the fore. In contrast, the wellbeing economy agenda promotes economic systems that deliver human and ecological wellbeing. It demands major transformation in businesses, infrastructure, work, decision making, and so on. Fortunately, there is good practice within a growing movement, including pioneering policymakers (such as the Wellbeing Economy Governments partnership).

**Keywords:** *Wellbeing Economy, System Change, Social Justice, Sustainability*

### Introduction: A fork in the road

COVID-19 has revealed that enormous shifts in policy are possible. Alongside extraordinary changes in behaviours have come extraordinary changes in policy and spending by governments. Policies previously dismissed as ‘unrealistic’ are being seriously discussed and levels of government intervention that would have been baulked at in many countries are now being rolled out. This constitutes a perhaps unprecedented fork in the road for societies and economies around the world. Could this mean that 2020, the year a virus did so much harm to so many, becomes the catalyst for long overdue economic system change that places human and ecological health and wellbeing at the centre?

### Normal was the problem

Is the economy of pre-COVID-19 days, with its dependence on growth and with GDP as its key performance indicator, one that is worth trying to return to?

The pandemic has revealed that the workers who really keep European societies going are often underpaid in precarious jobs: workers hitherto dismissed as ‘low skill’—the couriers, the supermarket staff, the care workers, and the refuse collectors. But during lockdowns they are keeping the essential shops open, the streets clean, delivering groceries (and books and jigsaws the more privileged turned to), and caring for sick and older people.

> #EHFG2020 – Opening plenary link:  
<https://www.youtube.com/watch?v=b-uO-3SN5J4>

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Equally, just as the cleavages in labour markets have been laid bare by COVID-19, inequalities that pervaded societies (such as the United Kingdom<sup>9</sup>) pre-COVID mean that its impacts are being felt in dramatically different ways for different people. Some people will suffer terribly, and some will not – from the health threat, from lockdowns and from the subsequent economic upheaval.

“  
economic  
systems need to  
be structured in  
a way that  
delivers human  
and ecological  
wellbeing

Why go back to an economy that treats many of our most essential workers so badly and which implicitly tolerates such inequalities? The economic systems of some countries generate insecurity, despair and loneliness, which spurs desperate searches for ways to cope, whether at the pill box or the ballot box.

Now that the extent to which government can shape the economy has been revealed, a return to the ways of the pre-COVID economy would be to consciously *choose* an economy rife with injustice – and which in turn has driven the earth to the brink of the 6th mass extinction<sup>10</sup> with the prospect of catastrophic climate break down getting closer and closer.<sup>11</sup>

The root cause is how the economy is currently designed – in a way that does not account for nature, in a way that is blind to distribution of resources, and in a way that puts measures of progress such as short-term profit and GDP to the fore.

In ‘developed’ countries, the benefits of growth are entering a stage when they bring less ‘bang for their buck’ (what

economists would term ‘diminishing marginal returns’). Indeed, for countries with higher GDP per person, a lot of what is counted as growth (rises in GDP) is driven by helping to fix and clean up the harm done in its pursuit.<sup>12</sup> For example:

- Cleaning up after a flood that was caused by a warming climate
- Hospital care for people who are stressed and turn to drugs
- Medical treatment for people whose asthma is made worse by the pollution in our streets
- Night shelters for people made homeless
- Security guards and CCTV cameras because citizens are scared of each other

Many of these expenditures have their roots in an economic system that has created inequality and poverty and that does not take good enough care of the environment. This begs a course correction: a new purpose for the economy and a new political ambition to deliver it.

### A wellbeing economy

The idea of *wellbeing* is not new. What the combination of the term “wellbeing” with the “economy” conveys, is that economic systems need to be structured in a way that delivers human and ecological wellbeing. An economy designed explicitly and concertedly to deliver social justice and a healthy environment constitutes a substantial *repurposing* of the economy away from its growth orientation. It demands major transformation in the operation of businesses, the design of infrastructure, the nature of work, decision making mechanisms, international relations, provision of basic needs, and so on.

The idea of a ‘wellbeing economy’ has been gaining attention in recent years. It has been the subject of an ‘own-initiative opinion’ of the European Economic and Social Committee (EESC), and All Party Parliamentary Group meeting<sup>13</sup> and an Early Day Motion in the UK Parliament,<sup>14</sup> supported in local council resolutions in Scotland,<sup>15</sup> covered by a flurry of media reports,<sup>16</sup> advocated in Prime Ministerial speeches,<sup>17</sup> and championed in a Ted talk by Scotland’s First Minister.<sup>18</sup>

Alongside this growing discussion is different interpretations of wellbeing. Contrasts between respective conceptualisations often relate to where to situate political responsibility and policy focus. For example, the call from advocates of subjective wellbeing is often for immediate treatment for individuals suffering stress and anxiety: for instance, investment in mental health support to help people survive and cope with current circumstances and thus to boost their reported wellbeing. Whereas advocates for the system change conceptions of wellbeing, while in agreement with the vital importance of helping people survive and cope with current circumstances, would point to the need to *also* pay attention to those circumstances themselves: the drivers of stress and anxiety, rather than settling for merely treating those who experience them.

This is where the wellbeing economy agenda comes in: with an explicit call for system change. Building a wellbeing economy means protecting people, keeping them safe, meeting their needs, ensuring their security (of income, of identity, and of body) and recognising the whole ecosystem in which people live their lives and maintain health. By reorienting goals and expectations for business, politics and society, I believe a wellbeing economy would deliver good lives for people, rather than allowing harm to be done that then requires much effort to attend to. It will not undermine people and the environment, and so will avoid having to deliver expensive downstream intervention to fix the damage caused by the growth focused economic model. For example, because the natural world is not being harmed to such an extent there would be less cleaning up, sequestration, and remedial work to be done; because people’s fundamental human needs<sup>19</sup> are being met, there would be less need for costly downstream acute intervention efforts to heal and fix the lives damaged by an extractive economy. In ensuring everyone is above a social foundation (see doughnut economics<sup>20</sup>), a wellbeing economy will address poverty, unemployment, illness, illiteracy, and homelessness. We know that more egalitarian societies are better for all their members: delivering better

health and higher life expectancy; fewer drug addictions; less violence; lower teenage pregnancies; higher wellbeing for children; lower obesity; less mental illness; and fewer people in prison.<sup>15</sup> A wellbeing economy could thus reduce the need for some costly state services, highly paid ‘downstream professionals’, and the politically fraught and inefficient process of redistribution. It is about actively building an economic system that is designed to deliver equitable distributions of wealth and opportunity whilst rejuvenating our planet.

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### Making it happen

Building a wellbeing economy is far from an easy task. Transforming an economy is a complex process that needs to cover many sectors. There will be new skills needed, new jobs and ways of working to embrace, new infrastructure to be built, new ways of measuring success to embed and new ways of working together to be forged. In a wellbeing economy, some industries will not be as large as they are now (if they exist at all). People working for those industries will need stable pathways to move to new work and ways found to ensure their incomes are secure (the ‘just transition’ conversation that unions, governments and others are exploring). Towns and communities that depend on these industries will also need help to adjust.

Hindering that shift is the extent to which many of our systems and institutions are designed: dependent on economic growth. Conversations about the economy are often framed with an assumption

### Box 1: Progress in building a wellbeing economy

By: Dorli Kahr-Gottlieb, Secretary General, European Health Forum Gastein

The concept of a wellbeing economy that moves away from focusing foremostly on economic growth and instead sees growth only as a good thing in service of the higher order goals of wellbeing, is increasingly recognised as a policy goal by a handful of governments.

**Scotland’s** First Minister, Nicola Sturgeon, considers economic growth as subservient to objectives to improve collective wellbeing.<sup>10</sup> This approach gives equal importance to tackling inequality as well as economic competitiveness, while ensuring a transition to a carbon zero economy where no one is left behind.

**New Zealand’s** government under the leadership of Prime Minister Jacinda Ardern has recognised the importance of a wellbeing economy and steps have been taken via the budget to ensure GDP growth is in service of wellbeing goals and in line with the values of the people. Priority areas include child poverty, mental health, the importance of fairness, and the protection of the environment – while aiming for a sustainable and low-emission industry for future generations and supporting businesses in this transition.

A group of governments have formed the Wellbeing Economy Governments partnership (WEGo), discussing the pressing economic, social and environmental challenges of our time with the shared ambition of implementing innovative policy approaches to build wellbeing economies. Members of WEGo are **Scotland, New Zealand, Finland, Iceland and Wales** who share the vision that “development in the 21st century entails delivering human and ecological wellbeing.”

The Economy of Wellbeing was also one of the **priority topics of the Finnish Presidency** of the Council of the European Union in the second half of 2019. Conclusions were adopted, calling on the European Commission and Member States to integrate a cross-sectoral economy of wellbeing perspective into all policy areas. The Council conclusions were adopted as a basis for further work on the concept in Europe.

that economic growth is *always* good – implying it is impossible to have too much or the wrong kind.<sup>14</sup>

Consequently, even in the midst of COVID-19, there is hyper change while simultaneously so much seems to be profoundly stuck. Change is hard and people understandably hold onto what they know, especially those who derive status and privilege from the current set up. On the one hand are the unprecedented trends buffeting people and planet (from COVID-19 and all its layers of turmoil to global warming and species loss to precariousness of livelihoods and vast inequalities); on the other, is an inability to break out of the conceptual straightjacket that offers only a narrow and inadequate set of solutions.

This means there is a risk that this window of possibility COVID-19 presents will close again very quickly – that a “rollback” will come as politicians rush to return to how things were. Despite the mounting evidence that people do not want to return to pre-COVID scenarios: in the United Kingdom for instance, polling in May 2020 revealed a majority of people wanted governments to prioritise health and wellbeing over GDP during the crisis<sup>15</sup> and almost two-thirds seeking big or moderate changes in how the economy is run in the future (only 6% of people reported wanting no changes).<sup>16</sup>

Fortunately, there are pockets of good practice to build on and a growing movement is forming around the idea of a wellbeing economy (**see Box 1**).

It comprises academics laying out the evidence base, businesses harnessing commercial activities to deliver on social and environmental goals, and communities working together not for some monetary reward, but following innate human instincts to be together, to cooperate and collaborate.

These efforts will be made so much easier the more pioneering policymakers (such as those participating in the Wellbeing Economy Governments partnership, **Box 1**) embrace the need for an economy that delivers human and ecological wellbeing. Such policies matter because for all the pioneers building a wellbeing economy in microcosm today, they will remain isolated until institutions, financial flows and more businesses are designed to be regenerative rather than extractive; until the tax system rewards activities and businesses needed for a wellbeing economy and discourages those counter to it; until prices of goods and services include full costs (for example, many polluting forms of travel do not price in their environmental impact); and until new measures of progress closer to what matters most to many people and planet replace GDP.

## Conclusion

At the end of the second world war, William Beveridge, the architect behind the United Kingdom's post war welfare system and National Health Service wrote on the opening pages of his report: 'A revolutionary movement in the world's history is a time for revolutions, not for patching' (quoted in <sup>17</sup>). COVID-19 has certainly created a revolutionary moment – the wellbeing economy could be the revolution that meets the moment.

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# THE ADVISORS' DILEMMA: INFORMED DECISION MAKING IN TIMES OF LIMITED EVIDENCE?

By: Isabella Röhring, Claudia Habl and Herwig Ostermann

**Summary:** The COVID-19 pandemic is a complex, multifaceted and rapidly changing challenge. In times of crisis, when scientific evidence is limited, fragmented or even missing, the application of the concept of evidence-based policy making is challenged and advisors face difficult times when providing guidance for policy makers. We argue that these dilemmas can be tackled by transparency, trust and open communication. This is not only between advisors and policy makers but also with the general public as handling the pandemic is a socio-political challenge that goes beyond the mere concept of emergency preparedness and rather impacts all areas of life and civil society.

**Keywords:** COVID-19, Crisis Response, Advisors, Politics, Knowledge Brokering

## The problem of flying blind

In December 2020, with most of Europe facing the second wave of the COVID-19 pandemic, the long-term challenge of dealing with the greatest public health crisis of the 21st century so far continues. Public health measures adopted for containing the pandemic are similar to those used during the 1918 flu pandemic, including limiting/forbidding gatherings (e.g. restaurants, bars, theatres, funerals), closing public institutions and services such as schools, quarantining and isolating infected patients, wearing face masks and encouraging hygienic measures like washing hands. More than 100 years later, emergency preparedness and national responses are still built on similar tools to cope with new public health threats.

Like the flu pandemic of 1918, the emergence of the COVID-19 pandemic has been surrounded by a high level of

uncertainty, for instance with regard to virology, epidemiology, public health and evidence-based policy making. Regarding the relation between advisors and policy makers, this raises essential questions as to how scientists or knowledge brokers can effectively advise policy makers when evidence is lacking. How can policy makers make decisions to protect public health and contain the spread of the virus without violating civil liberties? What degree of transparency of public relations is appropriate and who should actively communicate with the public in the age of social media?

The COVID-19 pandemic is characterised by new and often seemingly impossible dilemmas for experts and knowledge brokers when it comes to informing policy. During a fast-moving pandemic, when the risk of the public health threat cannot be accurately assessed, delaying interventions may cost lives. At the same time, the

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evidence base regarding the impact and long-term effects of individual strategies can be scarce to non-existent.

### Shift of challenges

What becomes immediately apparent is that crisis management is a multidisciplinary task and clinicians, scientists, knowledge brokers and policy makers depend on each other to effectively respond to the crisis, despite diverging interests.

From the very beginning of the COVID-19 pandemic, clinicians and scientists around the globe focused intensively on studying the new Coronavirus, accelerating clinical and non-clinical research. Medical disciplines like virology and infectious diseases, epidemiological data and health system capacity, specifically hospital capacity and the protection of vulnerable groups, were of primary interest. Meanwhile, the scientific community is being supported by additional funding and the European Commission has already assigned €459 million to 103 research projects (September 2020) and funding will reach €1 billion by December 2020.<sup>2</sup> Established mechanisms like peer-review processes and access to scientific results on COVID-19 have been adapted to make research results quickly available and publicly accessible.

Country comparisons, cross-country data and information exchange between European Union (EU) countries rapidly

gained in importance. However, many challenges occurred when collecting cross-country data due to different health care systems, methods of data collection and reporting. Health data on COVID-19 is still fragmented and, when no alternatives are available, it is legitimate to use what is available. However, these limitations should be communicated transparently.<sup>3</sup> Besides collecting and merging data, compliance with statutory data protection regulations and accurate interpretation of the data are crucial. For example, do countries with a higher reported mortality rate have a greater number of severe cases, did the capacities of their health care system already reach their limits or was testing limited to specific patient groups? The need to answer such questions emphasises that a structured exchange of health data and information at EU level

to promote surveillance and emergency preparedness is necessary to prepare for and deal with current and future disease outbreaks.<sup>4</sup> Current European projects, i.e. the Joint Action on Health Information or to-reach: Transferring Innovation in Health Systems, are already working on creating an EU Health Information Research Infrastructure and setting up a joint European research programme on health systems and services.<sup>5 6</sup>

As the pandemic progresses, the focus has shifted from medical specialities to public health in its broadest sense. Aspects came to the fore regarding the mitigation of the wider effects of the COVID-19 pandemic on health and health care, e.g. mental health and medical care for stroke or cancer patients as well as economic, legal and political aspects. The effects of public health measures introduced during the COVID-19 pandemic on health systems, society and economy are leading to another challenge that has to be dealt with after the pandemic.

“impossible to disentangle science from policy”



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## The art of advising

Although existing research is available and accessible, the results are still fragmented and judgements on the effectiveness of different interventions are problematic.<sup>3 7</sup> Appropriate multidisciplinary skills are necessary to assess the immense quantity of clinical and non-clinical research on COVID-19 and the quality of research results has to be ensured despite accelerated peer-review and publication processes. Ultimately, the analyses and combination of results can differ between protagonists.<sup>8</sup> Different interpretations informed by cognitive biases, knowledge and access to information by scientists, knowledge brokers, advisors, policy makers or the general public can lead to different conclusions.

In the face of scarce or conflicting scientific evidence, experts and knowledge brokers face difficult times advising policy makers. Advice is often based on expert opinion, it has to be provided in extremely short time frames and aspects have to be considered that are beyond the scope of an advisor's expertise, as a public health expert may not be an expert on water hygiene or public transportation. Despite the need for further expertise, additional research results do not necessarily make

experts' and advisors' lives easier. What if there are conflicting research results or still no research results on specific topics?

*'Precisely in crises, where decisions must be made quickly, openness about scientific knowledge – and knowledge gaps – is crucial.'* – Camilla Stoltenberg, Director General, Norwegian Institute of Public Health

Advisors have to be clear whether their advice is based on science or expert opinions and this has to be communicated transparently. Irrespective of the basis for given advice, policy makers can still value or interpret science differently. Moreover, policy makers tend to act on advice that fits with their pre-existing views and narrative. Regardless of the evidence base, policy makers still have to make decisions, revising them constantly when dealing with uncertainty.<sup>9</sup> If doubts occur about science, trust issues could arise between advisors and policy makers. These issues could lead to policy makers' decisions not taking the relevant science base into account and reflecting rather on personal beliefs.

*'Don't be afraid to say what you know, but equally important don't be afraid to say what you don't know.'* – Chris Fearne, Deputy Prime Minister and Minister of Health, Malta

Advisors need to be aware of the responsibilities that come along with advising policy makers. Their level of expertise and skills need to be decisive to meet policy makers' demands and to cope with potential dilemmas. Policy makers' differing agendas need to be addressed but advisors still have to be objective and independent. Public health experts serving as advisors might be advantaged compared to other disciplines as they may already be closer to politics in their field of activities. Overall, more public health expertise is needed and providing advice on health policy should be a discipline in itself. Specific training for advisors, be they scientists or public health experts, could help to address policy makers' needs better and avoid advisors' dilemmas.

The COVID-19 pandemic has highlighted that it is impossible to disentangle science

from policy and that the relation between advisors and policy makers has to rest on trust, openness and transparency.

## Does speed trump certainty?

Before the pandemic, health policy makers looking to make evidence-based policies would take research into account as soon as a certain level of evidence was available, i.e. in meta-analyses. During the pandemic, policy makers have had to make decisions based on limited evidence or no evidence was available. This raises the question as to how much evidence is needed to inform policy and whether it is needed at all. Is it legitimate to act without a sound evidence base when speed is of the essence?

“ a shift  
from academic  
to societal  
responsibility

The pandemic has illustrated that the basic concept of evidence-based policy making is not appropriate in emergency situations.<sup>10</sup> According to the precautionary principle, policy makers can take action in the absence of a sound evidence base. Existing knowledge gaps and dependence on expert opinion lead to policy makers making decisions that are based on assumptions rather than scientific evidence. In times of crisis, the public health community supports decision making based on the available information that is not fully evidence-based. Hence, being pragmatic is perceived as an adequate approach given the circumstances. But how transparently should policy makers communicate information on the virus or how they made their decisions to the public? Who should be in charge of managing that communication?

Emerging from the session, decision makers should be as transparent as possible in times of a crisis and disclose everything that is known about the pandemic to the public. Neither PR specialists nor scientists alone should

be responsible for the communication but politicians should also be involved, as they are responsible for decision making. A transparent, timely and open communication policy towards the public is also perceived as an appropriate strategy to counter misinformation, prevent the stigmatisation of specific groups and react to the networked contemporary society (see the article by Rajan and Koch in this issue).

### Pandemic crisis management: a socio-political challenge

Alongside interacting with society through transparent communication, society's willingness to comply with public health measures to tackle the spread of COVID-19 is crucial. Restrictions implemented in most countries of the European Union and beyond affect civil liberties. Even the impact of the pandemic and restrictions in the first lockdown influencing socio-economic inequities cannot be estimated as yet.<sup>1</sup> During the second wave, more is known about the virus and its consequences, e.g. with regard to disease progression and mortality in various age groups. As a matter of fact, citizens respond to restrictions in their civil liberties. If strict restrictions are re-imposed in the course of the second wave that citizens' feel limits to their fundamental rights, e.g. occupational freedom, specific actions are paramount to reduce their impact on socio-economic inequities.<sup>2</sup> For policy makers, it is therefore indispensable to find the right balance between implementing measures, protecting civil rights and communicating public engagement as one contribution to reducing the number of infections in times of exponential increases. This clearly indicates a shift from academic to societal responsibility.

### Policy lessons

Overall, the progression of the COVID-19 pandemic and measures taken to address it show that it is a socio-political challenge. Having the big picture in mind, we experience what 'health in all policies' implies. What we have learned is that in times of crisis, the pyramid of evidence-based medicine does not apply and research has to adapt to promote at least

informed decision making.<sup>3</sup> Fighting a pandemic is not a quick win but a complex and long-term challenge without clear limits and will require ongoing momentum to address the fallout for health systems, economies and society.<sup>4</sup> A variety of aspects have to be accounted for to deal with the situation, including clinical, scientific, public health, ethical, legal, cultural, social, economic and political issues. Professional expertise and skills across all disciplines are therefore key to managing a public health crisis, provided that everyone sticks to their field of expertise. Moreover, advisors and policy makers should follow rules of honesty and transparency and promote public engagement as part of the key to success while respecting fundamental rights.

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# THE POWER OF PARTNERSHIPS

## TO REALISE THE EU PHARMACEUTICAL STRATEGY

By: Karl Cogan and Lorraine Nolan

**Summary:** The future success of the European Union (EU) Pharmaceutical Strategy is inextricably linked to the establishment of new, or strengthening of existing partnerships between key stakeholders responsible for the delivery of quality, safe and effective medicines. Although one of many concerned players, medicines regulatory agencies will play a critical role as they are positioned at many key intersections along the lifecycle of a medicine that requires engagement with a variety of stakeholders. Greater integration, collaboration and partnership between actors from across the health care and industry sectors is critical to realising the goals and objectives of the EU Pharmaceutical Strategy.

**Keywords:** *Partnerships, Innovation, Policy, Medicines regulators*

### Introduction

Central to the success of the EU Pharmaceutical Strategy is the continued and timely access to quality, safe and effective medicines for European citizens, while also ensuring the European pharmaceutical industry remains an innovative world leader. These overarching goals are ambitious and take into account an ever increasing globalised approach to pharmaceutical development in addition to novel forms of evidence generation, utilisation and assessment while also ensuring a holistic patient-centred approach. Only through collaborative partnerships between patients and their representatives, consumers and health care professionals, academia and research organisations, industry, regulatory authorities, health technology assessment

bodies, and pricing and reimbursement agencies, can these laudable goals ever be realised.

The Pharmaceutical Strategy was developed against the background of a well-established medicines regulatory network with the European Commission, the European Medicines Agency (EMA) and the medicines regulatory authorities in the Member States working together to ensure access and availability of safe and effective medicines. Moreover, this strong regulatory network is combined with a robust and competitive pharmaceutical industry. Despite a relatively strong medicines infrastructure in Europe, ever more complex supply chains, rapidly changing global contexts i.e. COVID-19, innovation pipelines that are discordant with public and health system needs, and

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medicines shortage issues were some of the challenges the strategy needed to overcome. Given the range of potential threats to the integrity of the European medicines environment, it was clear an extensive number of players were required to address these issues. The new EU Pharmaceutical Strategy ultimately sets a policy environment that requires a renewed sense of shared purpose among key stakeholders and alignment of goals through collaborative partnerships to address the range of issues presented.

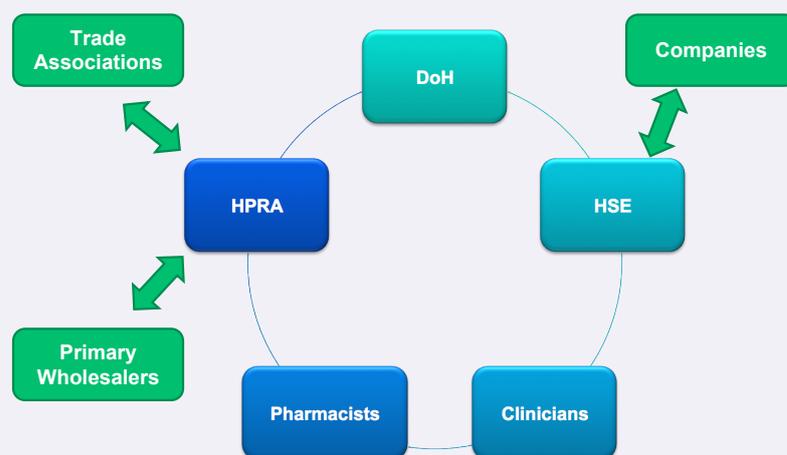
“Intelligent, data-driven surveillance networks will also inform regulators”

The synergies between the EU Pharmaceutical Strategy and emerging themes outlined in the joint European medicines agencies network strategy to 2025<sup>14</sup> – as adopted by the EMA and the Heads of Medicines Agencies (HMA) – are clear. The alignment of common goals and shared objectives enshrines the partnership between policy makers and regulators who oversee the system. To accomplish shared strategic goals and objectives, the importance of partnership extends to all stakeholders, and is the foundation upon which success will ultimately be achieved. Continued access and availability to life-saving medicines, in addition to supporting and enabling innovation, are central pillars common to both the EMA/HMA and EU Pharmaceutical strategies, respectively. While access, availability and innovation are incredibly important outcomes, the development of productive partnerships between key stakeholders is fundamental in realising the potential of both strategies to deliver for European citizens and the economy alike.

### Box 1: Ireland's Medicines Criticality Assessment Group

To provide a national example, the Irish Government convened the Medicines Criticality Assessment Group (MCAG), originally established to work on Brexit related supply issues, to avert potential shortages and reduce the impact on patients in response to the public health emergency. In addition to colleagues from our agency, the Health Products Regulatory Authority (HPRA), membership included representatives from the Department of Health, the Health Service Executive (HSE), and health care professionals (see Figure 1). While the Department has ultimate administrative responsibility for the health care system in Ireland, the HSE is charged with providing public health services in hospitals and communities across the country. In addition to internal intelligence sharing across many levels of the Irish health system, MCAG interacted with a range of key external stakeholders, including trade associations, primary wholesalers, and individual companies. This multi-stakeholder intelligence lead approach enabled the MCAG to have better oversight of the supply of medicines, and facilitated proactive strategies to better match demand for certain medicines by coordinating an increase in capacity, where possible, or identifying alternative medicinal products.

**Figure 1:** Medicines Criticality Assessment Group (MCAG) configuration to address potential shortages of critical ICU medicines in Ireland



Source: Authors' own

Note: HPRA – Health Products Regulatory Authority; HSE – Health Services Executive

Although medicine regulatory authorities are only one of the many concerned players, they have a critical role as they are positioned at many key intersections along the lifecycle of a medicine that requires engagement with a variety of stakeholders. From initial research and development to post-authorisation safety monitoring, national competent authorities will play a vital role in helping to achieve the goals and objectives of the EU's Pharmaceutical Strategy. While not an exhaustive list, the following examples provide an overview of how the cross-cutting nature of the EU Pharmaceutical Strategy

impacts regulators in the context of establishing new, or strengthening existing partnerships to deliver for European citizens now and into the future.

### Future Access to Medicines and the Role of “Big Data”

We have embarked on a digital revolution, where innovative technologies such as wearable and/or implantable sensors can generate an incredible amount of data that captures many aspects of our biology in granular detail, often in real-time. This type of data, for example, might

be collected to monitor the performance of a new therapeutic under real-world conditions to complement traditional large-scale randomised control trials. These data might also be combined with multiple-layer “omic” technologies\*, to generate an incredibly personalised biological fingerprint. It is not unrealistic to think that future marketing authorisation applications for medicines might include these integrated sources of real-world evidence to inform regulatory decision making concerning the potential safety and/or efficacy of new therapeutics. As a result, regulators will be required to adapt their processes to appropriately realise the potential of “big data” when determining the benefit-risk analysis of a medicinal product.

To address these challenges, and capitalise on the opportunities, the HMA and EMA have established a Big Data Task Force to review this area and its implications for competent authorities. A comprehensive report was published in 2019,<sup>2</sup> which subsequently led to the establishment of a multidisciplinary joint HMA and EMA Big Data Steering Group with membership from a number of key groups within the regulatory network as well as patient and health care professional representation.

As part of its mandate, the group is tasked with upskilling the European medicines regulatory network (EMRN), i.e. national competent authorities (NCA) with responsibility for medicines and medical device regulation, in big data. This includes the establishment of a training curriculum and strategy informed by analysis of the available knowledge and resources across the network. In recognition of the need to have access to additional expertise, it is envisaged that this will involve collaboration with external experts (including industry and academia) and also consider targeted recruitment of data scientists, omics specialists, biostatisticians, epidemiologists and experts in advanced analytics and artificial intelligence (AI).

\* omic technologies are types of laboratory-based analysis tools that generate large datasets used to investigate biological molecules, such as RNA, DNA and proteins, that provide insights into pathways associated with health and disease.

Sharing of information, expertise and resources is a central pillar of the EMRN. No individual agency will be able to tackle the potential challenges, or realise the opportunities, represented by the use of big data as real-world evidence. Promoting ‘cluster’ based approaches across the network represents an efficient approach to resource allocation to fully capitalise on the potential utility of new forms of data and methods of assessment. Only through collaborative partnerships between Member States within the network who have already developed expertise, in addition to external experts, can regulators fully embrace the potential of big data and new forms of evidence to facilitate continued access to medicines.

### Stakeholder Engagement and Availability of Critical Medicines

The COVID-19 pandemic has impacted on almost every aspect of our daily lives, including how medicines regulators operate. Medicines lifecycle management, good practice (GxP) inspections, and establishing mechanisms to support development and accelerated approval of therapeutics and vaccines to protect global public health are examples of challenges that regulators needed to overcome to sustain the health and well-being of citizens. At a basic level, ensuring a continued supply of Covid and non-Covid related medicines was a challenge, requiring coordinated engagement with multiple stakeholders to protect against potential shortages. See **Box 1** for a national example from Ireland on the establishment of the Medicines Critical Assessment Group (MCAG) to mitigate against shortages.

Intelligence generated from the MCAG was also shared with European counterparts, thus creating an integrated intelligence network. The potential of MCAG-like systems to feed into wider regional networks is obvious, and extends beyond the current pandemic environment. The success of intelligence-led oversight of medicines availability and supply is fundamentally built on collaborative partnerships between all stakeholders responsible for health care delivery. Intelligence, data-driven surveillance

networks will also inform regulators on how best to develop new procedures that enable greater capability to react, but more importantly pre-empt, potential shortages. Ultimately, integrated partnerships like the MCAG will facilitate continued supply of safe and effective medicines to protect our citizens.

### Vibrant Ecosystems Supporting Innovation

The pace at which innovative medicines and health technologies are developing represents a real challenge for regulators. Although advance therapeutic medicinal products (ATMPs), convergence between medicines and medical devices, and digitalisation of health care are all examples of innovative technologies with potential to significantly change patient health, it is imperative novel therapies and technologies are effectively regulated while also facilitating safe and timely access. In responding to this challenge, while continuing to enable innovation, it is critical that regulatory authorities establish partnerships with a wide variety of stakeholders to facilitate appropriate regulation from discovery through to approval.

“the network performs early stage horizon scanning”

To ensure the regulatory system is well positioned to respond and support a dynamic life sciences environment, the European Innovation Network was established between national medicines agencies, and the EMA. Regional partnerships extend the expertise and knowledge network of Member States, with their academic sectors and other innovators. The scale of this pool, in terms of expertise and extended outreach, is beyond anything that has existed before. The network performs early stage horizon

scanning for the purposes of identifying disruptive and novel technologies and products. It is not just about identification, but also about determining the policy requirements and expertise required into the future. Access and regular interaction with regulatory bodies throughout the early lifecycle of an innovative medicine through official procedures can help guide clinical development programmes and help developers navigate regulatory requirements.

It is important to realise that for medicines to be considered truly innovative in the context of clinical benefit, they should demonstrate meaningful impact on patient care and well-being at least equal to, but preferably above, currently available therapies.<sup>2</sup> For example, a pharmaceutical company might develop a novel compound targeting a new biological mechanism of action to treat a particular disease. If this compound, however, has no additional benefit compared to existing treatments, can it truly be considered innovative? It is important to disentangle innovative science from innovative care and subsequent clinical utility<sup>†</sup>. While targeting novel biological mechanisms with new compounds is and of itself an innovative approach, without data supporting meaningful clinical benefit beyond existing treatments, it is unlikely to benefit patients.

Conversely, to ensure timely access to promising innovative medicines that deliver clinically meaningful benefits, medicine regulators should foster collaborative partnerships to enhance evidence generation for all actors across the health system. During scientific advice procedures, for example, medicines regulators should work collaboratively with health technology assessment bodies to pre-plan data requirements that satisfies both regulatory assessment but also generate the clinical evidence needed by downstream stakeholders. Greater understanding and appreciation of the requirements of other actors within a broader health system can facilitate access to innovative medicines through efficient and timely generation of necessary evidence.

<sup>†</sup> Clinical utility is a term used in medicine to describe the relevance and usefulness of an intervention in patient care.

## Conclusion

The establishment and maintenance of productive partnerships between multiple key stakeholders is vital for the EU's Pharmaceutical Strategy to ensure that European citizens have continued access to safe and effective medicines. Synergies between the pharmaceutical strategy and key themes in the joint EMA and HMA European network strategy enshrines partnership between the policy makers and regulators who discharge the system. Greater integration, collaboration and partnership between actors from across the health care system and industry colleagues is key to success.

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# DANCING TO NEW TUNES TO REDUCE INEQUALITIES IN CANCER PREVENTION AND CARE IN CENTRAL AND SOUTH EASTERN EUROPE

By: Wendy Yared, Christoph C. Zielinski, Antonella Cardone, Darina Sedláková and Christiane Thallinger

> #EHFG2020 – Session link:  
<https://www.ehfg.org/conference/programme/sessions/tackling-access-inequalities-in-cancer-care>

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**Summary:** Cancer and other health outcomes vary widely across Europe, especially between Western and Central and South-Eastern Europe (CEE) countries. While progress has been made, gaps are still wide. We must do more by employing new strategies, such as analysing inequalities by addressing the entire spectrum of cancer control, and with a cross-sectoral approach. The Central European Cooperative Oncology Group (CECOG) is an example of such a collaboration, with the goal of overcoming inequalities in cancer care in the CEE.

**Keywords:** Cancer Prevention, Inequalities, Treatment Access

## Introduction

Unacceptable inequalities in cancer prevention and care is a hugely important and persistent problem that exists between Western and Central and South-Eastern Europe\* (CEE) and within countries according to socioeconomic status. The figures for survival rates are especially stark.

It is expected that the gap between East and West will widen further due to the ongoing COVID-19 pandemic, where prevention and health promotion campaigns have been frozen, and

screening, patient support, treatment, and other cancer services have been severely disrupted.<sup>1</sup>

It is now therefore more urgent than ever that actions are taken and with a collaborative approach. A timely session on “tackling access inequalities in cancer care” took place at the European Health Forum Gastein in October 2020, which provided perspectives on the challenges and issues in the CEE related to policies on cancer prevention, access to care, and health literacy. Cross-sectoral stakeholders highlighted the dire effects inequalities have on cancer patients and their families and friends. Key messages included the need for bold new political initiatives

\* Bulgaria, Croatia, Czechia, Hungary, Poland, Romania, Slovakia, Slovenia.

and the introduction of a comprehensive Cancer Dashboard covering the entire spectrum of cancer control and specifically addressing CEE.

## Cancer Prevention

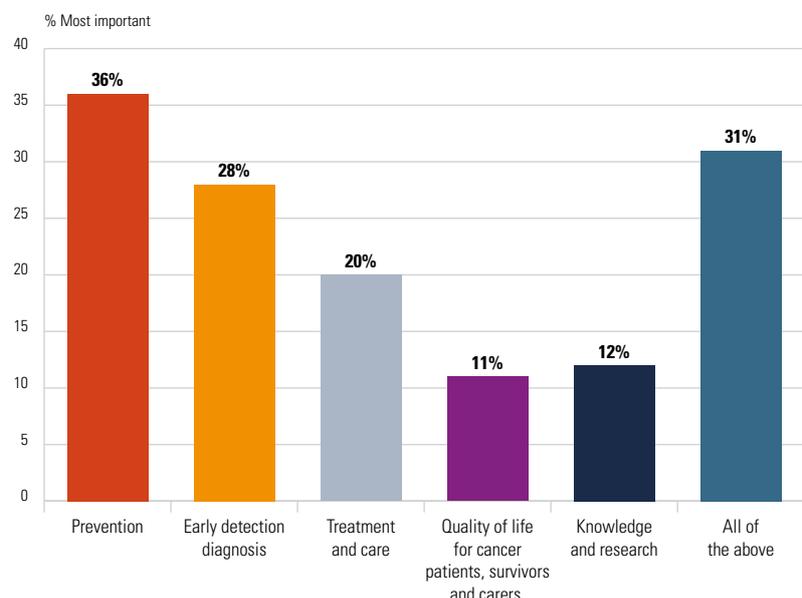
Health promotion and disease prevention is a common vein that runs through the work of all health sectors. Prevention will be a prominent feature of the Europe's new "Beating Cancer Plan" being launched at the end of the year, as prevention is the "easiest and most effective way of reducing cancer in the EU".<sup>2</sup> European citizens agree. The public consultation for the Beating Cancer Plan found that more than half of respondents would like to see the Plan give prevention more attention. This was confirmed by a poll of the more than 200 participants during the European Commission's townhall meeting on 10 September 2020 (see Figure 1).

“Up to 50% of cancers can be prevented

Yet, CEE countries are less able to invest in cancer prevention, even though such investments can improve the health status of the population and reduce health inequalities. In Slovakia, for example, prevention accounts for only 1% of health spending, versus the EU average of 3% which is already low considering the importance of prevention.<sup>3</sup>

Up to 50% of the cancer burden can be prevented.<sup>4</sup> The European Code Against Cancer, developed by the International Agency for Research on Cancer, has 12 recommendations providing advice to the general population on actions to take, related to tobacco use; second-hand smoke; body weight; physical activity; diet; alcohol consumption; ultraviolet radiation (UVR) exposure; occupational carcinogens; radon; breastfeeding; hormone replacement therapy (HRT);

**Figure 1:** Which do you think is the most important area of focus for EU level action and for Europe's Beating Cancer plan success?



Source: Mentimeter poll, Townhall Meeting on Europe's Beating Cancer Plan, 10 September 2020.

human papilloma virus (HPV) and hepatitis B virus (HBV) vaccinations; and screening (bowel, breast and cervical).<sup>5</sup>

## Access to Care

The industry representative, Deepak Khanna of MSD, highlighted at the Gastein session that European countries invest only 4–7% of health expenditure in cancer. This is surprisingly low given that cancer may very well be on its way to be the top disease burden in many countries, overtaking cardiovascular diseases. He also pointed out that modelling showed that earlier access to care can result in the gain of life years, and in the prevention of additional adverse events. This would result in savings for the health care system, something especially important for low resource countries (see session recording). In order to achieve this, however, would require an analysis and update of the current reimbursement systems.

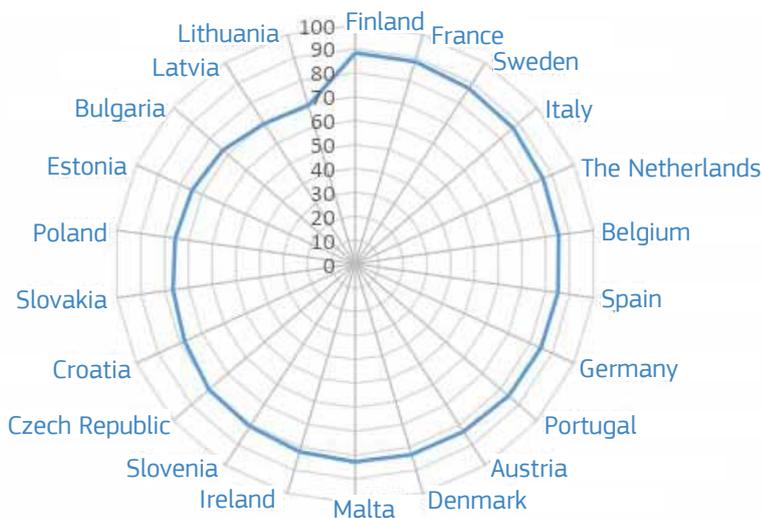
## Health Literacy

Khanna also stressed that closing the inequality gap between countries would also require improving health literacy, which is linked to being one of the most important investments in cancer care. If

we are to include the role of citizens, it is critical that they have a competent level of cancer and health literacy.

While digitalisation was not discussed during the Gastein session due to lack of time, it is important to remember that health literacy is linked to digitalisation. Digital health literacy is not only an issue for patients, but for health care providers as well. The European Commission is creating a common European Health Data Space (EHDS), with the aim of promoting better exchange and access to health data to support health research and health policymaking. The EHDS has the potential to address inequalities, for example, by providing quality eHealth services to reach underserved communities and across borders. For the EHDS to be a success, however, patients and the general public must be sufficiently literate to understand the issues of digitalisation, including privacy, the right to share or not share their data, and the importance of supporting the interoperability of data so that when they wish to seek cancer services across the border, they can be sure that their data has also travelled with them if they have given consent. During the COVID-19 pandemic, we have seen eHealth services boosted by

**Figure 2: Breast Cancer Survival (Ages >15, cancers diagnosed in 2000–2007)**  
Percentage of patients who survived at least 5 years after diagnosis



Source: Reproduced from: [https://ecis.jrc.ec.europa.eu/pdf/Breast\\_cancer\\_factsheet-Oct\\_2020.pdf](https://ecis.jrc.ec.europa.eu/pdf/Breast_cancer_factsheet-Oct_2020.pdf)

necessity, but eHealth may not have been taken up fully, due to privacy concerns and lack of digital health literacy.

### The Patient's Perspective

The rise in inequalities in CEE is closely linked to demographic and lifestyle trends which are likely to persist or even amplify in the future.

There are many concrete examples of major disparities which exist in access to cancer care and overall survival rates across Europe. Gaps are significant when looking at 5-year survival rates for certain cancers across Europe:

- Colon cancer 5-year survival rates after treatment averaged 52% in Eastern European countries compared to 63% in Western Europe.<sup>5</sup>
- Cervical cancer incidence and mortality rates in Romania are three times higher than in other European countries.<sup>6</sup>
- For breast cancer, countries such as Bulgaria, Romania and Estonia have a low 5-year survival rate of 75–78% compared to Nordic and Western countries with a 82–87% rate.<sup>7</sup>

The European Cancer Information System published a striking contrast recently

showing CEE countries clustered on the lower spectrum of breast cancer survival (see Figure 2).

For all types of cancer, the range of 5-year survival rates can be as wide as 40% in Bulgaria to 64% in Sweden.<sup>8</sup> This is a result of inequalities across the entire cancer journey from diagnosis to aftercare and those from Eastern European countries are more likely to experience:

- Lack of access to early screenings which can lead to late diagnosis
- Limited access to affordable care, medicines, and trials
- Lack of information and awareness on their rights after cancer treatment.<sup>9</sup>

The European Cancer Patients Coalition, an umbrella organisation of cancer patient groups, urges that Member States and the Europe's Beating Cancer Plan recognise the gaps by addressing them in National Cancer Control Plans (NCCPs) and implementing a standard set of guidelines to support them through every stage of the cancer journey – prevention, diagnosis, treatment and aftercare.

A helpful and vital first step, would be the accessibility of data and the importance of efficient and up-to-date cancer registries in each country. Organisations such

as the Central European Cooperative Oncology Group (CECOG) are creating committees from across Western, Central and South-Eastern Europe with the aim of harmonising cancer treatments across these countries. This research can be used as an example as to how we should move forward with cancer data at the EU level. Addressing these issues is complex as the needs of Western Europe and South-Eastern Europe differ and consistent data is needed to pinpoint these differences.

“gaps are significant when looking at 5-year survival rates

Currently, only 6 of 13 CEE countries have national cancer care plans in place. It will take health care organisations, patient advocacy groups, stakeholders, politicians and policymakers to come together to implement these changes. Investment in research, education and training to retain professionals in the clinical communities is also important, as well as recognising the importance of the patient in the role of treatment. In conclusion, there is a long way to go and many important steps to take before inequalities can be addressed across Europe. But with cohesive guidelines, data-collection and the proper patient information across Europe these changes can be possible.

### The Policymaker's Perspective

Mr Cristian Busoi, Member of the European Parliament (MEP) from Romania, is widely respected for his dedication to improving health for European citizens. At the Gastein session, he pointed out that while the situation of inequalities has improved somewhat, it is not by much. Mr Busoi gave his commitment to continue working with key stakeholders to use the current momentum to address disparities with a specific proposal.

## A Cancer Dashboard for Central and South-Eastern Europe

A comprehensive tool for addressing inequalities in the CEE countries is through an ambitious Cancer Dashboard, developed by CECOG. CECOG was founded more than 20 years ago, under the Chairmanship of Professor Christoph Zielinski, with the original objective of harmonising treatment standards across Western, Central, and South-Eastern European countries. The ever-persistent problem of health inequalities between and within countries drove CECOG to create the Governmental International Affairs (GOIA) initiative two years ago. This active multi-stakeholder collaboration connects committed scientific leaders, policymakers, payers, patients and industry representatives to work together on solutions and to expand the focus to the entire cancer pathway—prevention, screening, early diagnosis, access to state-of-the-art cancer diagnosis and treatment.

“expand the focus to the entire cancer pathway”

This Cancer Dashboard includes not only an analysis of shortcomings, but also concepts with defined plans and key metrics for the measurement of suggested achievements (see Box 1).

CECOG believes it has generated a viable document which analyses shortcomings in cancer care in CEE, and at the same time to have suggested solutions and key performance indicators to measure the success of their implementation.

It would be useful to see the CEE Dashboard become part of the EU Cancer Plan currently being developed by the European Commission.

### New Tunes

The EU has always been committed to addressing health and cancer inequalities in partnership with the Member States. An important example is the policy report

### Box 1: Elements in the Cancer Dashboard for CEE

#### Recommendations

- for prevention and cancer control,
  - national cancer prevention and control programs
  - population-based screening programs and cancer registries
- for reimbursement decisions on and access to newly EMA-registered compounds,
  - the implementation of the ESMO Magnitude of Clinical Benefit Scale
  - abbreviations in decision times regarding reimbursement on the national level
- increased appreciation of patient advocacy groups as important stakeholders and their involvement in
  - increasing education regarding cancer-related issues including
  - participation in clinical trials
  - involvement in approval processes
  - cancer drug reimbursement
  - the analysis and subsequent monitoring of a “cancer patient pathway”.

#### Key Metrics

- for screening including the generation and monitoring of numbers of educational initiatives, awareness and prevention programs on cancer risk factors including the assessment of smoking rates in adults, percentage of inhabitants with obesity, number of women diagnosed with cervical cancer and other HPV- as well as HBV- and HCV-associated cancers (Key performance indicator (KPI): number of new cancer cases with early stage cancer in 2025–2030–2035)
- for imaging diagnostics and molecular testing, an increase in the regional coverage with and modernisation of state-of-the-art medical imaging tools (KPI: wait time for diagnostic imaging) and general reimbursement of molecular testing (KPIs: percentage of patients with molecular testing results and consequent individualised therapy)
- for radiotherapy and systemic treatments, an increase in the number and modernisation of machines and an increase in manpower (KPIs: wait time for adjuvant radiotherapy and number of people living with cancer for >10 years after diagnosis on 2025–2030–2035) and an ameliorated access to cancer drug treatments (KPIs: time between diagnosis and initial treatment, percentage of patients treated on a clinical trial at any time after diagnosis, percentage of patients presented to a multidisciplinary tumour board at any time after diagnosis), respectively, resulting in the assessment of overall survival by stage at initial therapy for individual malignant diseases.

on cancer inequities which was a part of the EU Joint Action on Cancer Control.<sup>10</sup> This second Joint Action in cancer control involving 25 European countries concluded that progress in cancer control is hampered by disparities in access to quality cancer care in Southern and South-Eastern European countries and published important recommendations.

During the current Joint Action Innovative Partnership Action Against Cancer (iPAAC), the theme of inequalities continues to be an important vein. One concrete example is the launch of a competition to identify “Best Practices tackling social inequalities in cancer prevention, including both health promotion and cancer screening

programmes” with the aim of promoting and facilitating their implementation across Europe.<sup>11</sup>

Key findings from the public consultation on Europe’s Beating Cancer Plan note that there are high expectations for the Plan, and that the public is urging the Plan to address the issue of “access and equity (which) are uneven both within and between countries across Europe”.<sup>12</sup> This year’s Gastein Forum invited all participants to explore new partnerships to “dance with elephants”, which CECOG and its Governmental International Affairs multi-stakeholder initiative have been doing gracefully. Health inequalities are still very much a problem, however. Let us now dance to new tunes, which should include the new hits of the CECOG Cancer Dashboard, and Europe’s Beating Cancer Plan.

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## The COVID-19 response webinar series

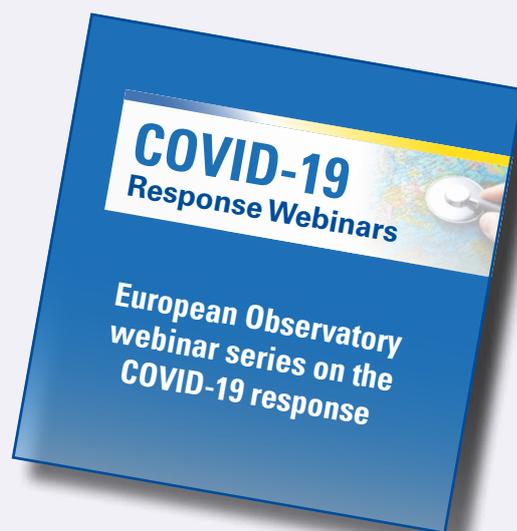
Europe’s governments are struggling to curb the spread of COVID-19 and to gear health systems up to meet new surges. They are implementing or tightening measures to prevent transmission and looking to strengthen infrastructure and workforce capacity, health services provision and health systems governance overall.

The European Observatory on Health Systems and Policies is running a series of webinars which draw lessons from country experiences with COVID-19. They will look at how health systems can respond to the pandemic and what makes them more resilient to external shocks and crises.

**Join the Observatory every Tuesday at 12pm CET for the webinar series.**

Forthcoming topics include:

- COVID-19 apps and the future of digital technologies
- COVID-19 lockdowns and their broader impact: social costs and potential co-benefits
- COVID-19 and health financing: sustainability and crisis budgets during the pandemic.



**For further information and to register see:** <https://www.covid19healthsystem.org/Webinars.aspx>

**The COVID-19 Health System Response Monitor (HSRM) is available at:** <https://www.covid19healthsystem.org/mainpage.aspx>

# FIGHTING HEALTH INFODEMICS: THE ROLE OF CITIZEN EMPOWERMENT

By: Raffael Heiss

**Summary:** As an increasing number of people receive and share health information on social media, misinformation and conspiracy claims have become prevalent on these platforms. To meet this challenge, a comprehensive strategy is necessary, with the empowerment of citizens at its heart. In this comprehensive strategy, big tech, expert organisations and governments have to contribute to reduce obviously false information on social media platforms. However, top down surveillance is not always possible or desirable. Citizens should also become more motivated and skilled to engage in corrective efforts when they encounter misinformation online.

**Keywords:** *Infodemic, Misinformation, Conspiracy Theories, Fake News, Citizen Empowerment*

## Introduction

The COVID-19 pandemic revealed some of the problems of today's high choice media environment, in which information is no longer exclusively produced by professional "gate-keepers", such as educated journalists. In fact, everyone can create or share content and disseminate it through large online networks. This of course has a huge potential for widening political discourses and for empowering citizens to express themselves at any time. Yet it poses a challenge, because, unlike professional journalists, many citizens do not have the necessary time nor skills to select the most relevant and trustworthy content from the myriad of information pieces in the digital world.

As a result, we are confronted with increasing levels of mis- and disinformation online. **Misinformation**

describes the unintentional sharing of false, inaccurate or incomplete information. For example, some citizens may share false information on COVID-19 treatment because of a lack of literacy and knowledge. **Disinformation**, by contrast, describes the intentional spread of such information, for example based on political or commercial motives. This combination of strategic disinformation and the unintentional sharing of such content contribute to our current information environment, which the World Health Organization has labelled as an *infodemic* – "an overabundance of information and the rapid spread of misleading or fabricated news, images, and videos".<sup>1</sup>

In this context, it is important that citizens possess the necessary skills and knowledge to judge health-related

> #EHFG2020 – Session link:

<https://www.youtube.com/watch?v=Ymb09UjwIY>

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content in the digital world and are motivated to correct it if necessary. Research in communication studies has shown that citizens can contribute to prevent the spread of misinformation by linking to trustworthy expert sources, such as to content from the WHO. To this end, citizens need low threshold access to fact checking information, so that they can easily identify and correct encountered misinformation.

“citizens need low threshold access to fact checking information”

### Is correction even possible?

There are reasons to assume that misbeliefs are hard to correct.<sup>2</sup> This is especially true for attitudes and knowledge structures around issues which are emotionally loaded. For example, people with extreme attitudes (e.g. political or religious) are more likely than others to accept attitude-congruent false information and, once incorporated in their worldview, are specifically resistant to question the “facts” behind this construct.<sup>3</sup> The tendency of choosing information based on prior attitudes rather than on relevance and truthfulness is called selective exposure or selection bias.<sup>4</sup> Beyond selecting attitude-congruent information, people with extreme attitudes may also engage in motivated reasoning processes, in which they focus on processing information which is in line with their prior attitudes, and refute information which challenges them.<sup>5</sup> In other words, for some individuals, misinformation about COVID-19 can be used to justify their strong views, such as a heavy distrust against the government or big corporations.

However, not all shared misinformation is suitable to foster strong beliefs and not all online users have extreme positions.

Furthermore, there is reason to believe that even rumour spreaders with more extreme positions can be corrected by strong ties in their social media network, i.e. people with whom they have a close connection.<sup>6</sup> Thus, even though correction may not always be easy, there is still a huge potential to be unleashed.

### The role of expert sources

Health-related information on social media can be corrected by algorithms, such as Facebook’s “related news” approach,<sup>7</sup> or by citizens themselves. Either way, existing studies hint to the importance of expert sources in the corrective effort.<sup>8,9</sup> Such expert sources may include the WHO, but also local health agencies or academic institutions. Citizens may sometimes feel that encountered information may be wrong or imprecise, but they often lack the necessary knowledge to correct misinformation off the top of their heads. They also often lack the time and skills to engage in an in-depth information search. As a consequence, responsibility cannot be easily delegated to the citizens. In fact, regional expert organisations, such as local health agencies, have to provide the necessary facts and make them accessible to citizens. To this end, they need to penetrate social media with factual content, monitor prevailing misbeliefs, and counter them by providing or promoting fact-checking tools which are easily accessible. There are already plenty of English language fact-checking websites available, such as the charity [fullfact.org](http://fullfact.org) or the private company [leadstories.com](http://leadstories.com). Yet, the available information still needs to be translated and adapted to regional contexts.

### Empowering citizens

While the cooperation of big tech companies, expert organisations and governments is a prerequisite to help citizens navigate health infodemics and fight the spread of misinformation, the empowerment of citizens might become the key to success for three reasons.

*First*, while algorithms can only detect obviously false or extreme content, humans can also identify content which is slightly inaccurate or incomplete and

contextualise it, for example because citizens have personal knowledge about the people in their network. This is highly important, because encountered content is often not completely false. However, vague information or even the expression of fear can create climates of uncertainty. For example, some people are concerned that the aluminium used in vaccines may increase their risk of Alzheimer’s. A look on the fact-checking website [fullfact.org](http://fullfact.org) reveals that there is a lack of scientific evidence for this link and that a person in general “ingests seven to nine milligrams of aluminium per day” through their diet, while a single vaccine contains less than a milligram.<sup>10</sup> These are important arguments, which can be used to counter expressed fears of vaccination.

*Second*, rumour spreaders may often judge corrective efforts based on the relationship they have with the correcting source. For example, a corrective effort of a close friend may have a more persuasive effect than one from a distant contact.<sup>11</sup> For example, if a close friend comments on a post which includes misinformation, the rumour spreader may take the post down or reply by admitting the falsehood, thus making the post less influential in the network. This may not only work on social media platforms, but also when citizens confront rumour spreaders in personal talks or private messages. Such corrections by close contacts may then have a lasting effect, even on more resistant rumour spreaders.

*Third*, active citizens are the best guarantee for a resilient democracy. In fact, big tech companies, the government and expert organisations are supposed to work in the interest of citizens. However, big tech companies also have strategic business interests, such as reaching wide circulations. False news is often designed to stimulate virality\*,<sup>12</sup> which may impede big tech’s motivation to ban such content entirely. Moreover, government surveillance of the online space may also allow for non-democratic censorship. For example, the Hungarian government has instituted a five-year sentence for disseminating misleading information, [leading to fears from journalists it](http://www.hungarytoday.com/news/hungary-five-year-sentence-for-disseminating-misleading-information)

\* Virality is the tendency of an image, video, or piece of information to be circulated rapidly and widely from one internet user to another.

could disrupt objective reporting of the pandemic and the government's response.<sup>10</sup>

## Boosting Knowledge

People with more extreme positions may be more inclined to believe and share information which supports their worldview regardless of the truthfulness of this information. However, misinformation is also often shared because of a lack of literacy to find, appraise and understand health-related content, and thus to acquire health-related knowledge.<sup>11 12</sup> However, existing research indicates that knowledge is an important protective factor, inoculating individuals against misinformation.<sup>13</sup> Survey data collected at the peak of the COVID-19 pandemic in Austria<sup>†</sup> indicate that citizens with less knowledge are more likely to believe and share misinformation.

“the empowerment of citizens might become the key to success

In the survey, knowledge was measured with quiz questions (e.g., knowledge of the terms ‘herd immunity’ and ‘incubation period’, or the ability to identify people who belong to the ‘at-risk groups’). Citizens with low knowledge were more inclined to rate the claim that *being able to hold breath for 10 seconds is a good test for COVID-19* as credible. Similarly, people with low knowledge were more likely to deem the assertion that *the coronavirus was spread to stop population growth* as credible. Furthermore, citizens with less knowledge reported that they have shared misinformation which was detected as such by others more frequently than citizens with more knowledge. Boosting citizens' knowledge may thus indeed protect them against falling for online misinformation.

† For details on the study visit: <https://research.mci.edu/en/cshi/blog/covid19/sample>

## The road ahead

To tackle the current and future health infodemics, governments in Europe need to think about how to strengthen and empower active citizenry in their countries. One prerequisite is the enhancement of literacy in the field of health, politics and new media technology. Navigating new digital environments has become more complex and more demanding and the acquisition of knowledge in these environments requires new skills. Thus, new and innovative educational programmes are needed. Furthermore, public campaigns may target public awareness of social media misinformation and encourage young people to become active in correcting misinformation online. In the event that citizens encounter questionable health information, they need low threshold access to in situ fact checking information from trustworthy sources. Governments, expert organisations and also big tech companies need to engage in an open, bottom-up discourse on what tools and content citizens need. For only when citizens are motivated, equipped and surrounded by opportunities, can their full potential to fight the current and future health infodemics be unleashed.

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# THE HEALTH DEMOCRACY DEFICIT AND COVID-19

By: Dheepa Rajan and Kira Koch

**Summary:** The COVID-19 crisis has laid bare the need for robust governance in health. Advice to political leaders on COVID-19 strategies was largely provided by specialist experts or those with an established relationship with government bodies, reflecting a default governance mode which is still not inclusive. Populations, communities, and civil society were largely left out; yet, inclusive dialogue initiatives are crucial to building trust and policy adherence. Social participation, although not novel in theory, is innovative in practice as decision-makers still struggle with the ‘how’ of fostering health democracy and bringing people’s voice into emergency responses and health policies.

**Keywords:** Health system governance, Social participation, People-centredness, COVID-19 response, Universal health coverage

## The Covid-19 response: the need to cast the expertise net more widely

When the scale of the COVID-19 crisis became apparent in early 2020, countries had to make swift decisions about which public health and social measures would be most effective to slow down transmission and reduce mortality associated with COVID-19. Policymakers took these decisions under immense political pressure and a sense of overwhelming urgency (see the article by Röhrling et al. in this issue); in some countries, these decisions were only taken when Coronavirus infections and hospitalisation rates skyrocketed. Such measures encompassed movement restrictions; closures of schools, cultural sites and businesses; geographical area quarantines and international travel restrictions.

These decisions were generally made by governments following advice from task forces that were newly formed or

reactivated to advise the government response. Despite the far-reaching consequences for society beyond health and medicine, the task forces in most countries were dominated by virologists and epidemiologist-modelers. Besides the narrow specialist focus, COVID-19 governance lacked overall inclusiveness with regards to gender, geography, sexual orientation, race, socio-economic status or disciplines beyond health, excluding the very perspectives, expertise and lived realities which were needed to tackle virus transmission at its weakest spots.<sup>1</sup>

COVID-19 outbreak response decisions are still taken based on a predominantly medico-technical paradigm. In other words, the pandemic is perceived first and foremost as mainly a viral, medical and public health challenge by those sitting on decision-making bodies. Even within the health space, specialists from other medical fields, such as mental health,

> #EHFG2020 – Session link:  
<https://www.youtube.com/watch?v=PCkeYfgH-ql>

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child health, chronic diseases, preventive medicine, and gerontology, are not or are insufficiently represented – the same holds for the non-health specialists such as social workers, child development specialists, and human rights advocates. If at all, many of these experts are often only consulted as an afterthought or in secondary discussions; during the first wave in Spring 2020, the major collateral consequences of confinement measures such as disruptions in the essential health services as well as increased domestic violence, child abuse, food insecurity, etc. were thus not adequately anticipated with targeted alleviation measures.<sup>2</sup>

### Civil society and community groups were largely left out of COVID-19 decision-making

Not only was the specialist expertise net cast narrowly, but also other types of experiential expertise failed to be heard by policymakers. Civil society and community groups were poorly or not at all represented on COVID-19 advisory task forces, echoing growing criticism by health experts and researchers that the COVID-19 response “largely involved governments telling communities what to do, seemingly with minimal community input”.<sup>3</sup> Yet civil society and community groups are closely embedded within the community and societal fabric, possess insight into the day-to-day challenges faced by vulnerable groups (e.g. older people, disabled, single mothers, migrants etc.) disproportionately affected by COVID-19 measures, and can conduct risk communication in a language which is understood by their peers.

Anecdotal evidence provided by civil society groups demonstrates that the consequence of leaving out civil society voice in COVID-19 decision-making can be dire: a poignant example comes from a French dialysis patients’ association’s experience of rapid viral transmission in their constituency at the start of the pandemic due to a dearth of protective equipment for staff and patients.<sup>4</sup> This led to overly strict measures imposed by authorities with little consultation with affected parties. A mask mandate combined with a ban on eating and drinking during dialysis sessions was

one such measure – one which is hardly feasible when dialysis sessions last up to 7–8 hours including travel time from home to dialysis centre. It also raises key questions about quality of life, human rights, and dignity – information which merits reflection, at the very least, as part of the decision-making process.<sup>5</sup>

Civil society’s insights also stem from their own, very active COVID-19 response efforts, which, unfortunately, was mostly wholly disconnected to the government one. A rapid UHC2030 Civil Society Engagement Mechanism (CSEM) survey conducted in the middle of the first pandemic wave in April 2020, with over 200 civil society responses from 58 countries, confirmed that, in the majority of cases, civil society’s response efforts were independent from the government response.<sup>6</sup> Some civil society members lamented that when they did manage to get government’s attention for urgent matters, it was a cumbersome process as no formal, well-functioning communication channel existed between governments and civil society.

### Enriching research-based evidence with experiential knowledge for improved health decision-making

The lack of diverse expertise and voices in advisory and decision-making bodies reflects what is generally valued as ‘evidence’ by policymakers. Evidence is clearly “largely understood to mean research-based evidence, and not necessarily experiential, implementation-based evidence from the field”.<sup>7</sup> Despite its significant relevance for policy, real-time experiential knowledge is underestimated, while it is the information coming precisely from the lived experiences and everyday challenges faced by people – such as the dialysis patients in the above example – which allows for adapted and feasible virus mitigation measures which a population is willing and able to adhere to.

The current understanding of ‘evidence’ and ‘science’ are, again, rooted in the traditional biomedical view of health and not necessarily the holistic practicality of health as it plays out in people’s daily lives. Thus, epidemiological facts and figures are

scrutinised at great length by government and advisory bodies; qualitative research or quick surveys examining the plethora of factors impacting vulnerable groups and marginalised parts of societies are still relegated to lower priority and not given adequate policy consideration.

### More transparency and trust is needed

The COVID-19 pandemic has caused a sizable trust deficit between governments and populations in some parts of the world.<sup>8</sup> Trust and transparency go hand in hand; governments in general have not been transparent about the considerable trade-offs involved in deciding which measures to take, when, and why. For example, two recent studies castigate the lack of public disclosure of information on who is consulted by advisory and decision-making bodies, which members had which viewpoints, which weight was given to which reflections, and even the composition of the governance bodies themselves.<sup>9</sup> <sup>10</sup>

Especially trade-offs need to be made more explicit to justify far-reaching measures depriving populations of basic freedoms, with the aim of giving people good reason to adhere to them. In an environment which easily fosters fake news and protest marches against COVID-19 restrictions, a high level of transparency can form the basis of a communication strategy which addresses what those trade-offs means for people’s daily lives.

### The remedy? Institutionalisation of social participation mechanisms

HIV/AIDS patients’ activism of the 1980s led to the motto of ‘nothing about us, without us’. This movement is remarkable for the inroads it made in including the HIV/AIDS community – not only patients themselves but family members and the wider LGBTQ+ population – in HIV policy formulation. The result has been people-centred, adapted, and responsive health services for affected patients, contributing to declines in HIV prevalence and increasing numbers of patients adhering to long-term treatment regimens.<sup>11</sup>

The HIV/AIDS example demonstrates the win-win that can be achieved by greater collaboration between government and civil society to address population health problems. Countries where that collaboration is regular, formalised, and/or institutionalised in normal times seem to be able to better leverage established channels of communication and coordination in service of a health emergency response. A case in point is the National Health Assembly mechanism in Thailand which convenes civil society, academia, and government once yearly to debate, and more importantly, find solutions for public health issues.<sup>1</sup> The Assembly resolutions serve as recommendations for policy, and is prepared for 12 months with citizen hearings, forums for interaction between government, civil society, and lay-people, and many other events. Those established channels of dialogue were easily re-activated during the COVID-19 crisis to understand and adapt COVID-19 communication and response measures to the living conditions and needs of different population groups.<sup>2</sup> This was mainly possible because the relationship of trust and familiarity of context existed before the crisis arose, and formed a solid foundation which allowed for a joint approach to tackling COVID-19 transmission.

“learn to engage more broadly with populations, communities, and civil society”

An example from Europe is the nascent National Health Council (NHC) in Portugal, a government advisory body whose membership consists of civil society, professional associations, and government representatives. Founded in 2017, its principal aim is to ensure an inclusive debate on priority health matters which feed into official recommendations

for policy.<sup>3</sup> Although the NHC was not formally included in COVID-19 decision-making, the NHC took advantage of its mandate and convened working groups to reflect more broadly on society's needs during the pandemic. Government debates picked up on the results of those NHC discussions as it provided valuable information directly from communities. This quick and trusted access to civil society offered by an institutionalised mechanism for social participation was thus recognised as a national public good to develop and refine further in the future.

### Conclusion: the need to change the 'default' mode of governance

As the pandemic rages on, governments are losing out on trust and policy adherence if they do not learn to engage more broadly with populations, communities, and civil society. Besides its dire necessity in the current emergency mode, social participation mechanisms need to form the backbone of how a health system is steered. Emerging reports of countries where closer government-civil society collaboration facilitated the pandemic response indicate that institutionalised social participation structures embedded in the health sector landscape played a significant role. Yet the 'default' mode of governance as is currently on display in the vast majority of countries tackling the COVID-19 crisis does not do justice to a pandemic which is not only a health problem but a societal one,<sup>4 5 6</sup> where trust in institutions and adherence to virus mitigation measures can make or break the success of the pandemic response.<sup>7 8</sup>

While many caveats exist for formal mechanisms of social participation, their clear added value is the regularity of interaction as well its mandatory nature.<sup>9</sup> Despite a certain level of discomfort it may bring, key health topics of broad societal interest must be discussed by, with, and for people from all walks of society, with differing and opposing views. It means that the messy task of dealing with potent interest groups and conflicts of interest needs to be confronted head-on for the sake of finding a solution to pressing health problems. Doing so can lend legitimacy to whatever decision is

taken, however difficult or controversial, and facilitate communication and implementation of subsequent policy measures.

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We asked some key participants to share their perspectives on the concept of a European Health Union

The **European Health Union** is an initiative with potential to shape European politics for decades to come



By: Vytenis Povilas Andriukaitis  
Former Commissioner of Health and Food Safety, European Commission.

> #EHFG2020 – Closing plenary link:

<https://www.youtube.com/watch?v=cl4POWg44D4>

**From the very beginning, the European project was about saving lives. When the French foreign minister, Robert Schuman, delivered his famous Declaration on 9 May 1950, he was outspoken about the importance of eliminating war in Europe. 70 years of largely peaceful development of the continent is proof that his project for peace, for saving lives, works.**

The relative role of the health sector in European countries has grown in the latter half of the 20th century. The latest available Eurostat figures on the Eurozone (2018) show that employment in health is now almost twice that in the combined economic sectors of agriculture, forestry, fishing, mining and manufacturing of basic metals that dominated European policy at the start of European integration.

Unfortunately, until 2020, development goals such as promoting good health and longevity were off the radar of big European policy. For decades health-related matters were considered by the EU almost exclusively as the business of Member States or quasi markets for a number of reasons including that health policy is a national competence, the inertia of political thought (as some considered health an unproductive sector), the neoliberal approach to the EU as a common market, and opposition from traditional industries.

The COVID-19 pandemic has revealed the limits of preparedness to mitigate the negative impact of health emergencies on economic growth, employment, fiscal balances, international trade, free movement of people and may well prove to be a game changer in the acceptance of the role health has to play in European policy. Since the early spring of 2020, health has dominated media coverage and national and international debates. During the European Health Forum Gastein 2020 the change of political sentiments was nicely described by Tamsin Rose, Senior Fellow, Friends of Europe: “Health has been

the Cinderella of public policymaking for a long time, nobody would listen, and we never got to go to the ball. Now we are the equivalent of the princess at the ball and everyone wants to dance with us”.

The term “A European Health Union (EHU)” was coined in spring 2020 and a few months later was catapulted to the rank of official EU policy by the European Commission President, Dr Ursula von der Leyen, in her “State of the Union” address.<sup>1</sup>

Europeans are demanding more pan-European actions for health (for example, as indicated by a 2020 Eurobarometer<sup>2</sup>) and EHU may provide the answer.

Different scenarios can be envisaged to develop EHU:

- Measures to make progress in health concentrate on what can be done with existing legal, financial, and managerial instruments, upgrading already functioning institutions, and improving implementation of already agreed policies.
- Fine tuning of existing instruments of health policy in parallel to the development of secondary legislation and establishment of new institutions that can create added value for European health. The scenario does not foresee amendments to the European Treaties.
- Europeans decide that in addition to “a” and “b”, a scenario “c” is needed, where the status of health policy in the European Treaties is strengthened, with provisions for a European Health Union incorporated into the Treaty on European Union, giving the European Union some competence in health policy in very concrete areas, while preserving the principle of subsidiarity as a core.

All three scenarios have their own advantages and disadvantages. None is perfect and none can be implemented immediately. A scenario “c” is, of course, the most ambitious. The best choice, in my opinion, would be to adopt this scenario. By opting for scenario “a” or “b” Europeans would restrict the benefits they would obtain from deeper cooperation on health.

The actual development depends on political choice, thus on outcomes of political debates. The European Council and the Conference on the Future of Europe are the right platforms for these debates. An agreement to consider the incorporation of provisions for a EHU into Articles 2 and 3 of a revised Treaty on the European Union, giving the EU explicit competence to take action on health policy would be the perfect outcome of the 2020–2021 political season.

The EU has potential to transform itself from being the block that cares about free movement of goods, people, services, and capital to a Union where lives and the health of all residents matter. But it will take time and efforts.

Proponents of EHU are aware that for many EHU looks like a nice political slogan that will fall out of fashion in line with the disappearance of quarantines and face masks, but they are inspired by the words

of Robert Schuman: World health “... cannot be safeguarded without the making of creative efforts proportionate to the dangers which threaten it”.

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## What do we actually mean by a ‘European Health Union’?

By: Anniek de Ruijter  
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**Almost a year after the global outbreak of the novel coronavirus in the beginning of 2020, we can now see the first signs of what the significant legislative and policy impact of this pandemic might be. In what may end up being one of the most notable outcomes, the European Commission has come up with a set of proposals<sup>1</sup> that would establish a ‘European Health Union’. At the same time, in a more bottom-up fashion, a manifesto<sup>2</sup> has come out on ‘a European Health Union’ as well. Importantly, as the German Chancellor signed off on the German Presidency of the Council of the European Union, Merkel clearly indicated her support for the creation of a European Health Union.<sup>3</sup>**

This sequence of events might suggest that it is clear what a European Health Union would entail, but it is not. What is meant by a ‘European Health Union’ is completely dependent on the criteria outlining what it will be in practice.

So, what is a ‘European Health Union’? Or rather: what should it be? Even if the current plans are laudable – and politically steep – surely a European Health Union stretches beyond a narrow approach to dealing with health emergencies as proposed by the European Commission? Clearly, if only for efficiency, we need to strengthen public procurement for essential and emergency medical countermeasures; we also need improved coordination on health communication to European Union (EU) citizens during outbreaks; and perhaps even a strengthening of the executive power of the Health Security Committee – basically a stronger role for the EU in reacting to infectious disease threats/and other health threats that have a cross-border aspect. But a ‘European Health Union’ suggests more. The question is, how much more?

Will a European Health Union mean that, after its establishment, access to high quality care will be the same in all countries? This seems unlikely as the

current differences and inequalities between Member States are significant. At present, inequalities persist in a Union of states where the average life expectancy at birth is 80.6 years, yet drops to 74.7 years in Bulgaria and reaches as high as 82 and 83 years respectively in France and Spain. Additionally, out of pocket costs as a share of current health spending in the EU ranges from 9% in France to 47% in Bulgaria.<sup>1</sup>

Can we call it a European Health Union when public inoculation programmes are exactly the same; mortality is calculated on the basis of a unified methodology; and the basket of available health care that is insured, is similar across Member States? Far from it, I would say. And there would not be many observers who would, at this point, normatively argue for such a level of EU integration in the field of health, nor would they empirically see this as feasible in the short or middle-long term. Although we should never be under-ambitious when it comes to health, we should always be skeptical, in my view, of simple positions on the European project that more integration is always better.

However, when over the summer a diverse group of people in the EU health community started coming together, a lot of the conversation – that first focused on exactly the COVID-19 response measures and infectious disease management policies that the Commission has recently proposed – quickly broadened beyond the emergency frame. Indeed, the conversation expanded to broader ideas about how to “load” the concept of a European Health Union with substantial and constructive policy ideas and ideals that can all be found at [www.europeanhealthunion.eu](http://www.europeanhealthunion.eu).

Being part of the European health community used to give one a little time to think. That is to say, there were many important networks proposing policies or responding to them, but as an observer, one would be able to keep up with developments. This was due to two slowing factors: Firstly, the basic tenet of EU health policy was the unwillingness of Member States to let go of powers in the field and the lack of capacity at EU level (not of ambition). Secondly, where at Member State level public health and health care policy is more integrated as a matter for policy and politics, in the EU there is more fragmentation in the field. We see a large body of regulatory policies and laws in the EU in the area of public health, but very limited possibility of ensuring access to health care in any sense that it would touch on a solidarity pact of Europeans to share the risks of disease and mortality. That is to say that the locus of power and actual ‘steering’ power in the EU on health is harder to identify, which can cause political inertia and delays.

So, when a group of concerned people, academics, policy experts, representatives of patients and public health advocates interested in EU health policy and law started to come together online, we were all trying to make sense of the quick developments, and the immense political pressures, breakthroughs and set-backs we were seeing – all at the same time – in the field of EU health. While we first started to come together as an exercise of sense-making, this quickly moved to a call to action in a series of meetings in various groupings. Mostly this was fed by the concern for a move towards short-term, ad hoc and quick solutions. We came together in the context of the European Observatory on Health Systems and Policies, the Vilnius European Institute of Health and Sustainable Development, and as policy ideas became more developed, the preliminary meetings culminated in several meetings in the context of the European Health Forum Gastein 2020. Importantly, a large group of patients’ organisations and civil society that were already part of the Europe4Health initiative also joined, with a great Young Gasteiner Michele Calabro from the European Patients’ Forum (EPF) co-chairing with Zoltán Massay-Kosubek from the European Public Health Alliance (EPHA).

What has come out of this process is the current *Manifesto for a European Health Union*,<sup>2</sup> that takes a much broader approach to where the EU can have a clear added value together with the Member States, outside of emergency reflexes and short-term solutions. As we move towards the Portuguese Presidency and toward the Conference for Europe, we bring this Manifesto to national parliaments, and national governments to take forward into a future EU.

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# If you want a stronger EU: build a European Health Union

By: Ilona Kickbusch  
 Founding Director and Chair of the Global Health Centre of the Graduate Institute for International and Development Studies Geneva, Switzerland.



**In her first annual State of the European Union (EU) address, European Commission President Ursula von der Leyen said the coronavirus pandemic had underlined the need for closer cooperation in health: “For me, it is crystal clear – we need to build a stronger European Health Union”\*.**

This momentum must be upheld. That is why there is now an initiative – see the MANIFESTO† – to promote the idea and several concrete proposals towards a European Health Union. Each health crisis – as with BSE, SARS, Ebola – has added a health policy layer to the EU and created new institutions. In this tradition of institution building, one proposal for a European Health Union suggests strengthening the European Centre for Disease Prevention and Control (ECDC) and European Medicines Agency (EMA), creating a new EU Health Emergency Preparedness and Response Authority (HERA), while others call for one fully integrated European Health Agency.

But many argue for a Treaty change. A health solidarity clause has been proposed in the case of a pandemic. It would work in a similar way as the EU civil protection clause and include a health stress test – like the stress test that applies to the banking system in the EU. Such an approach requires a treaty change because it brings important links to a fiscal union – for example if a country faces major financial crisis and this affects their health system.

In the face of the COVID-19 crisis there is a new opportunity to call for increased EU competencies in the field of health, and a growing appreciation of how many other areas of EU policy impact health and pandemic preparedness and response. The complexity this brings is to find the right form of integration and cooperation for the EU and its Member States to act more effectively together in health, in both “normal”

and pandemic times; and to do so in solidarity with the rest of the world based on the Sustainable Development Goals (SDGs).

In a world of rapidly changing geopolitics and power relationships, all eyes are on Europe to see how it will act. Many commentators say that the weakening of the USA is also related to its divisions and lack of social security – including health care. A global actor must be credible based on the actions within its borders. I believe that the EU must work to overcome the approach chosen following the financial crisis when in 2010 health was subjected to economic governance procedures which deeply intruded into national health care policies and systems with major equity consequences. Precisely because decision makers did not define the EU as a health union in the crisis of 2008/9, the EU paid a high human and political price for championing health sector austerity. One of the largest challenges will be how to build European solidarity and strengthen European sovereignty in relation to health without reinforcing nationalisms and regionalism. I feel that this is so important that it should form an important part of the *Conference on the Future of Europe* to be held this year.

So today, the debates on the purchasing and sharing of COVID-19 vaccines must be resolved, with the EU being recognised as a responsible actor by its Member States, the European citizens and by the world at large, especially by the poorest countries. In relation to health – European and global – the EU can be a critical actor to help the world build a joint health future based on the SDGs. The components are already mapped out in other EU policy arenas such as the economy of wellbeing, the green deal, the resilience and recovery fund, and the digitalisation agenda – but now is the time to add the “*health and wellbeing agenda*”. The high political and economic relevance of the interface between European and global health would, in my opinion, merit a European Commission Vice-President for Health and Wellbeing.

This double responsibility of a European Health Union is best expressed by first and foremost

\* [https://ec.europa.eu/commission/presscorner/detail/en/SPEECH\\_20\\_1655](https://ec.europa.eu/commission/presscorner/detail/en/SPEECH_20_1655)  
 † <https://europeanhealthunion.eu/wp-content/uploads/2020/12/Manifesto-for-a-European-Health-Union.pdf>

building on the *EU Pillar of Social Rights* and the commitment of the EU and all Member States to the SDGs. This means a European Health Union would promote wellbeing for all people of all ages within and outside of its borders (as per SDG-3). As the European Observatory on Health Systems and Policies has shown us, the EU already has a wide portfolio of health policy especially through its regulatory role towards its Member States for example in areas such as [Patients' rights in cross-border health care](#), [Pharmaceuticals and medical devices \(pharmacovigilance, falsified medicines, clinical trials\)](#), food safety and tobacco.

From this follows the global influence through the “Brussels effect” that leads to factual adoption of EU legislation in the context of the EU’s global market power. The possibilities to expand the dimensions of EU health policy action are considerable indeed.

The joint EU/G20 global health summit, planned together with Italy during its presidency of the G20 in May 2021, provides an opportunity for clarifying the next steps towards establishing a European Health Union that lives up to its double responsibility: within Europe and for the world at large.

## Forthcoming publications from the European Observatory

### In the Wake of the Pandemic: Preparing for Long COVID

#### Policy Brief

By: S Rajan, K Khunti, N Alwan, C Steves, T Greenhalgh, N Macdermott, A Morsella, E Angulo, J Winkelmann, L Bryndová, I Fronteira, A Sagan, M McKee, and COVID-19 HSRM country authors

A proportion of people experience persisting ill-health following the acute manifestations of COVID-19. There may be several reasons for this, but among them is the condition that is now termed “Long COVID”.

Long COVID can be severely disabling, with implications for the ability of those suffering from it to function. Although there is no simple symptom or test for diagnosing it, many people experience severe fatigue and a range of troubling physical symptoms that make it difficult for those who are employed to return to work. This has obvious economic consequences.

Given the many unanswered questions about this condition, research is a high priority. The forthcoming policy brief describes some of the ongoing studies being undertaken in Europe, following up those affected and conducting detailed clinical assessments. Some of these are creating cohorts of patients, something that will be of great value for the evaluation of potential treatments. This policy brief seeks to raise awareness of Long COVID and to provide a resource for those in decision making roles, setting out in basic terms what we know about this condition and what the policy options are for developing a comprehensive response.

### Regulating the unknown: A guide to regulating genomics for policy-makers

#### Policy Brief

By: GA Williams, S Liede, N Fahy, K Aittomaki, M Perola, T Helander, M McKee, A Sagan



Rapid advances in genomics hold huge potential to transform health and health care for the better. However, they also raise a number of critical questions such as over ethical use of data, privacy and security. Many of these challenges are not new and are similar to those for other health-related and personal information. Genomics nevertheless creates additional issues due to the sensitivity,

longevity and usefulness of data collected that can be continually reanalysed and reinterpreted as new knowledge and big data analytic tools emerge, and also because it reveals familial and not just personal information.

While developing appropriate regulation to protect patients and consumers may be challenging, it is not impossible and much work in this area has already been undertaken. This brief highlights the best-practice examples of how these issues have already been addressed through legislation such as the GDPR and other protective mechanisms in Europe and further afield. The authors nonetheless argue that many regulatory and enforcement challenges remain ahead of us to ensure that advances in genomics are used to their full potential on the basis of shared European values.

# The importance of **cross-border pandemic preparedness**

By: Raquel Medialdea Carrera

Epidemiologist, European Programme for Intervention Epidemiology Training (EPIET), European Centre for Disease Prevention and Control (ECDC), Sweden; Infectious Disease Control and Prevention Unit (IDCU), Health Promotion and Disease Prevention Directorate, Ministry of Health, Malta.

**COVID-19 has already become the most devastating pandemic of the century, with an enormous impact on the health and wellbeing of citizens across Europe and the world.**

Unfortunately, it is possible that the worst may be yet to come.<sup>1</sup> Nevertheless, many other pandemic threats should also concern us. Since the revised International Health Regulations (IHR) entered into force in 2007,<sup>2</sup> the World Health Organization (WHO) has already declared six Public Health Emergencies of International Concern (PHEIC) including the influenza H1N1 pandemic in 2009, Polio in 2014, the Ebola epidemic in West Africa in 2014, the Zika virus epidemic in 2016, the Ebola epidemic in the Democratic Republic of Congo and COVID-19 in January 2020.<sup>3</sup>

“  
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the area of  
pandemic  
preparedness

Pandemics are not a new thing and the world must be prepared for them to occur every few years. Importantly, we also cannot overlook the dozens of epidemics affecting two or more European Union (EU) countries every year. For example, in 2020 there have been several cross-border health threats of international concern in the EU beyond COVID-19,

including outbreaks of measles, influenza, West Nile Virus, Vibrio, Dengue and multiple foodborne related epidemics.<sup>4</sup>

In the light of these, and the catastrophic health and socioeconomic impacts of COVID-19, policymakers and public health experts should be prioritising the revision and improvement of all our pandemic preparedness plans in the EU. We need updated health policy that can regulate, support and contribute to the early detection of epidemic threats, rapid control of outbreaks, and elimination of pandemic threats at international, national and sub-national levels. We should start effectively applying the lessons learnt from COVID-19 and developing strategies for a rapid and robust public health response to epidemics in Europe in a coordinated way. Pandemics know no borders, therefore the scope for EU coordinated action on epidemic preparedness, pathogen research and promoting a multisectoral response mechanism has become more relevant than ever.

Many international public health organisations such as WHO, the European Centre for Disease Prevention and Control (ECDC) and the Global Outbreak Alert and Response Network (GOARN) have contributed remarkably to support all EU Member States in the fight to tackle this pandemic. However, there is much more that we should be doing. In view of the current situation, we need to develop stronger cooperation in the area of pandemic preparedness that could be prioritised by a potential European Health Union. We ought to set out the principles of the EU's future public health strategy. Pandemics disproportionately affect the most vulnerable populations and we need to ensure we protect all, with no discrimination.

This is a call for action for solidarity, cross-border collaboration and united coordinated action in Europe to prevent and control further epidemics. This is also a call to ensure we reorganise the health agenda to prioritise public health and epidemic research in the EU research agenda, the development of vaccines, improved diagnostics for infectious diseases, and better overall pandemic preparedness and emergency plans. The time for action is now.

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# The collision of two pandemics: Time for action

By: Margot Neveux

Policy Manager, World Obesity Federation, London, United Kingdom.

**Today, we are living in a new nutrition reality where rates of overweight and obesity globally keep rising with no signs of slowing down.**

At the 2013 World Health Assembly, governments around the world committed to reach the nine voluntary targets outlined in the *Global Action Plan for the Prevention and Control of NCDs 2013–2020*.<sup>1</sup> Among them, target 7 calls to “halt the rise in diabetes and obesity [based on 2010 levels].” Yet, whereas other targets related to non-communicable diseases (NCD) and risk factors such as reducing tobacco use and increasing access to cardiovascular disease medications are progressing positively, the *Obesity: missing the 2025 global targets* report shows that most countries have less than a 10% chance of meeting the obesity target.<sup>2</sup> The global prevalence of **overweight and obesity** nearly doubled between 1980 and 2008, and according to the latest available data, obesity affects 10–30% of adults in the European Union (EU).<sup>3</sup> Similar trends can be seen in children: as highlighted in the World Obesity Federation’s *Atlas of Childhood Obesity*,<sup>4</sup> 4.3 million children between the age of five and 18 years were living with obesity in the EU.

**Poor diets** are now the main risk factor for the global burden of disease.<sup>5</sup> Amidst the current COVID-19 pandemic, the World Health Organization (WHO) has highlighted that NCDs are a risk factor for becoming seriously ill with COVID-19,<sup>6</sup> and more recently emphasised increased levels of risks for people living with obesity.\* It is therefore essential for

governments around the world to ensure that obesity and other NCDs are recognised and integrated in national responses to the pandemic. But COVID-19 has also shed light on the disfunction of our current food systems and increased levels of **food insecurity** among the most vulnerable. The EU Farm to Fork Strategy recognises that the region is a global leader in providing safe and nutritious products, but flags persisting inequalities, with 33 million people unable to afford a quality meal every second day, while 20% of the food produced is wasted.<sup>7</sup>

*“The COVID-19 pandemic has underlined the importance of a robust and resilient food system that functions in all circumstances, and is capable of ensuring access to a sufficient supply of affordable food citizens”<sup>8</sup>*

The pandemic is giving the EU an opportunity to ‘build back better’ and develop more equitable and integrated food and health systems to **promote healthy lifestyles** and halt the rising prevalence of obesity. There needs to be transformative national and EU-policy approaches to address the interrelated pandemics of obesity and COVID-19, which must address underlying inequities to ensure #HealthForAll and a #HealthyRecovery. Governments need to ensure that their **national response plans** integrate and address malnutrition in all its forms, including undernutrition, overweight, obesity, stunting, wasting as well as other NCDs.

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\* Through a policy dossier, World Obesity Federation is collating known evidence, resources and materials pertaining to obesity/NCDs and the current outbreak of COVID-19. It can be accessed here: <https://www.worldobesity.org/resources/policy-dossiers/obesity-covid-19>

# The Vital Role of **Performance Intelligence** in Managing (Post-) COVID-19 Health Systems

By: Damir Ivanković

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**“Nothing in life is to be feared, it is only to be understood. Now is the time to understand more, so that we may fear less.” Marie Skłodowska Curie**

Right now, there is a tremendous opportunity out there. An opportunity to use the available data to understand the factors that hinder optimal performance of healthcare systems, and to identify impactful and manageable ways of addressing them. Data, performance, understanding and impact – those are some of the key concepts of the discipline of *performance intelligence* in health, which can be defined as “the structured approach to acting on health policies, using knowledge and information generated by the application of scientific methods to comparable healthcare data to systematically measure indicators of health systems performance.”<sup>1</sup>

Simply put, to work with performance intelligence is to *measure*, to *govern* and to *utilise*. This includes measuring how health systems and services perform, setting up performance-based governance mechanisms and using this intelligence to steer and support policy actions.<sup>2</sup>

Indicators count! They represent quantified *measures* of health service and system quality, and need to be meaningful, scientifically sound, generalisable, and interpretable.<sup>3</sup> Indicators should come with a clear purpose and should be fit for use. They are not perfect and come with comparability, actionability and adaptability issues, but they are the best we’ve got. And, with time and effort, indicators also keep getting better.

Results-based *governance* is a way of thinking about leadership and

management where health system and services performance data, turned into actionable information and knowledge, are integrated into meaningful health care governance mechanisms.<sup>1, 2</sup> This presents a transformation from data-focused health systems based on accountable organisations to data-driven learning health systems based on the integration of services. Strategies to support such transformation include improving ownership of the data (by both patients and service providers), enhancing competencies in harvesting the potential use of available performance data and dedicating sufficient resources to making the best out of what is already collected. This approach presents a shift from performance data being used solely as an accountability and scrutiny measure, towards one less focused on mandatory measurements and prioritising the use of data for decision-making.<sup>4</sup>

“using this intelligence to steer and support policy actions”

Using performance intelligence in policy- and decision-making allows health systems to be managed with a bi-focal perspective, incorporating both person-centred and population-focused approaches. It enables integration within and across health services, supporting the focus on areas and activities that matter the most now: pandemic response and

dual-track health system management, long-term care, mental health care, patient engagement, quality improvement (including outcomes), system resilience, transparent and accountable public reporting – just to name a few.

With all this potential of systematically and scientifically approaching performance intelligence in health, I believe the EU has to act. Supporting research and educational programmes such as the Marie Skłodowska-Curie Innovative Training Network for Healthcare Performance Intelligence Professionals (HealthPros) is an excellent start.<sup>2, 5</sup> HealthPros is an international training network providing innovative, collaborative, multidisciplinary, and entrepreneurial training 13 PhD students with varying backgrounds (e.g., health sciences, medical informatics, medicine, biological sciences, business administration, statistics, and economics). In six locations around Europe, HealthPros Fellows work on a cohesive set of individual research projects related to measurement, governance and utilisation aspects of working with performance intelligence. I strongly believe that a harmonised approach towards developing and using performance intelligence in health care—and creating a professional workforce to spearhead this process – should be one of EU action’s focus policy<sup>6</sup> areas in the upcoming years.

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## The **Economy of Wellbeing** for sustainable recovery

By: Kaisa Lähdepuro

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### The COVID-19 pandemic continues to ravage, but recovery planning is under way.

For the European Union (EU), the new EU4Health programme and the financial support to Member States' economic and societal recovery and resilience reflect the commitment of putting health at the centre of that agenda. With an economic downturn and with the lessons learned from the previous economic crises, it is timelier than ever to see the investment in health and wellbeing in light of its contribution to sustainable economic, social and environmental recovery.

The Economy of Wellbeing approach recognises that policies related to health, social protection, education, employment and skills, gender equality and the economy are interrelated.<sup>1</sup> Wise economic policymaking puts people at the centre, enabling and empowering them to harness

their capacities. Health is a fundamental right, but human and economic capital are interlinked.<sup>2</sup>

“wise economic policymaking puts people at the centre”

The Economy of Wellbeing offers a lens for looking at how to understand, evaluate and improve the economy *and* wellbeing, tackle existing inequalities, and prepare for the climate crisis and other threats. The pandemic has accelerated the discussion on the current concepts of the economy and growth,<sup>3</sup> demonstrated the importance of whole-of-society approach, and underlined the interlinkage between

the health of humans, animals and the environment (One Health). Digitalisation, in turn has supported effective responses and societal resilience, demonstrating value that might be difficult to quantify with current tools. The rapid digital leap has also underlined the importance of a rights-based, inclusive approach.

In many areas, the potential for positive return on investment in health surpasses the avoided costs of inaction. For example, the negative impacts of mental health on the economy are well known.<sup>4</sup> Supporting mental health during the pandemic in the short term is therefore fundamental<sup>5</sup> and the importance of positive mental health for societal resilience and recovery is clear. Tackling obesity, a risk factor associated with severe forms of COVID-19, would benefit both health and economies.<sup>6</sup> Strengthening preparedness through investments in essential public health functions and building resilient health systems would cost a fraction of the COVID-19 response and its impact on the

economy, whilst contributing to various health related goals and prioritising equity.<sup>7</sup>

Measurement and impact evaluation of, in particular, preventive measures remain a challenge.<sup>8</sup> A strategic vision of wellbeing goals and how to trace their achievement is necessary for meaningful analysis and action. Putting people at the centre requires understanding what matters and coupling it with strategic planning and budgetary and fiscal considerations. In some countries, the wellbeing approach is starting to be translated into practice with encouraging results,<sup>9</sup> and many, including Finland, are working together to exchange experiences on enhancing wellbeing and the economy.<sup>10</sup>

Responding to the pandemic has indeed highlighted the significance of global cooperation. The EU rapidly leveraged its support to the global response in a number of areas, including COVID-19 research, development and innovation as well as working with the World Health Organization (WHO) and other multilateral agencies. Understanding the economic rationale for global common goods for health will be critical for ‘building back better’ and for restoring the progress on the Sustainable Development Goals.<sup>11</sup> Recently, WHO established a Council on the Economics of Health for All with the aim of rethinking how health is valued. At the European level, a high-level Commission addresses health as a driver of sustainable development,<sup>12</sup> providing food for thought across the EU. Finally, the crisis is as global as it gets, calling for multi-directional learning and cooperation among regions.

It is clear that not learning from the crisis would be a critically missed opportunity. The good news is, learning can yield invaluable return on investment as well.

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# NEW PUBLICATIONS

## Building on value-based health care: towards a health system perspective

**By:** PC Smith, A Sagan, L Siciliani, D Panteli, M McKee, A Soucat, J Figueras

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Preoccupation with the value created by health systems has been longstanding, and will likely only intensify given the ongoing health systems strains and shocks such as the COVID-19 pandemic. But the focus so far has usually been limited to value as seen from the perspectives of certain actors in the health system and/or to certain dimensions of value. This policy brief calls for a shared understanding of value that embraces the health system in its

entirety, including preventive services and other public health functions. Herein, value is defined as the contribution of the health system to societal wellbeing.

A range of policy levers can be used to enhance value, ranging from cross-sectoral policies to involving patients in decision-making. While such levers normally focus on one or two dimensions of value, it is important to ensure that they do

not undermine other dimensions or the efforts of other actors. Effective governance of the whole health system is needed to ensure that stakeholder perspectives and policy levers are aligned to promote a common concept of health system value and, ultimately, of societal wellbeing. There are governance tools, such as the Transparency, Accountability, Participation, Integrity and Capacity (TAPIC) framework, that can help achieve this.

**Contents:** *Key Messages; Executive Summary; Introduction; Clarifying the key concepts: what do we mean by societal wellbeing and health system value?; How can various actors in the health system contribute to value?; Key policy levers for enhancing value: what do we know?; The central role of governance in aligning the levers; Conclusions; References.*



## Private health insurance: history, politics and performance

**Edited by:** S Thomson, A Sagan, E Mossialos

**Published by:** Cambridge University Press 2020

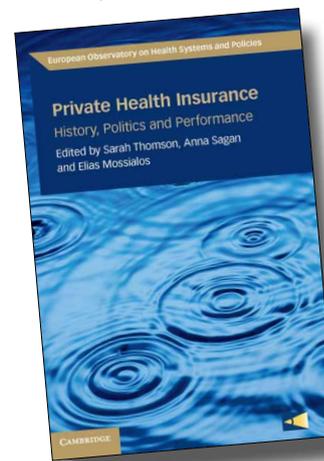
**Number of pages:** xviii + 574 pages; **ISBN:** 978 0 521 12582 6

**Freely available for download at:** [https://www.euro.who.int/\\_data/assets/pdf\\_file/0005/464297/private-health-insurance.pdf](https://www.euro.who.int/_data/assets/pdf_file/0005/464297/private-health-insurance.pdf)

Can private health insurance fill gaps in publicly financed coverage? Does it enhance access to health care or improve efficiency in health service delivery? Will it provide fiscal relief for

governments struggling to raise public revenue for health? This book examines the successes, failures and challenges of private health insurance globally through country case studies written by leading national experts.

Each case study considers the role of history and politics in shaping private health insurance and determining its impact on health system performance. Despite great diversity in the size and functioning of markets



for private health insurance, the book identifies clear patterns across countries, drawing out valuable lessons for policymakers while showing how history and politics have proved a persistent barrier to effective public policy.

This book is essential reading for graduate students, scholars and policymakers working on health systems financing worldwide.

**Contents:** *Acknowledgements; Why private health insurance?; Case studies on Australia; Brazil, Egypt and India; Canada; France; Germany and Chile; Ireland; Israel; Japan, Republic of Korea and Taiwan, China; Kenya; the Netherlands; South Africa; Switzerland; the United States of America; Index.*

# COVID-19 Health System Response Monitor

The COVID-19 Health Systems Response Monitor (HSRM) is an innovative platform which collects and organizes up-to-date information and enables cross-country analyses and comparisons of responses to the pandemic, as well as mapping wider public health initiatives, across the European region.

It was developed by the European Observatory on Health Systems and Policies with the World Health Organization Regional Office for Europe and the European Commission to systematically monitor health system responses to the COVID-19 pandemic.

<https://www.covid19healthsystem.org>

By combining this unique approach with links to important websites and essential data relevant to the pandemic and its impact, the COVID-19 Health Systems Response Monitor is a key resource for policy makers and those responding to the crisis.



# EUROHEALTH SPECIAL ISSUE: HEALTH SYSTEM RESPONSES TO COVID-19

In this special issue of Eurohealth, innovative public health and wider health system practices across the European region in response to COVID-19 are explored to understand what has worked (or not worked) in different settings. Clear policy lessons emerging from COVID-19 for the future of health systems are highlighted.

The analysis of COVID-19 responses collected in this issue constitutes a powerful testimony to efforts across Europe. It is also a stark reminder of the many unresolved structural problems in our health systems.

All the articles draw on the COVID-19 Health System Response Monitor (HSRM) platform, a major initiative led by the European Observatory on Health Systems and Policies, the WHO Regional Office for Europe and the European Commission.

Articles in this Eurohealth explore the following themes:

- Preventing transmission
- Ensuring sufficient workforce capacity
- Providing health services effectively
- Paying for services
- Governance

The COVID-19 Eurohealth special issue is available at:

<https://tinyurl.com/y3dyp3ym>

