

EHFG 2019 Conference Report
2-4 OCTOBER, BAD HOFGASTEIN, AUSTRIA

A HEALTHY
DOSE OF
DISRUPTION?
TRANSFORMATIVE
CHANGE FOR
HEALTH AND
SOCIAL
WELL-BEING

EUROPEAN
HEALTH FORUM
GASTEIN



List of abbreviations

AMR	Antimicrobial resistance
DG	Directorate-General
DG RTD	DG for Research and Innovation
DG SANTE	DG for Health and Food Safety
EC	European Commission
EMA	European Medicines Agency
EP	European Parliament
ERN	European Reference Networks
ES	European Semester
ESF+	European Social Fund Plus
EPSR	European Pillar of Social Rights
EU	European Union
EUR	Euros
GP	General practitioner
HAI	Healthcare-associated infections
HCP	Healthcare professional
HE	Horizon Europe
HIA	Health Impact Assessments
HiAP	Health in All Policies
HSPA	Health System Performance Assessment
HTA	Health Technology Assessment
IMI	Innovative Medicines Initiative
MFF	Multiannual financial framework
MS	Member State of the European Union
NCD	Noncommunicable disease
OECD	Organisation for Economic Co-operation and Development
OMPs	Orphan Medicinal Products
PHC	Primary healthcare
PPP	Public-private partnership
R&D	Research and development
R&I	Research and innovation
RWE	Real World Evidence
SDGs	Sustainable Development Goals
SPC	Supplementary Protection Certificate
RCT	Randomised controlled trial
Agenda 2030	United Nations 2030 Agenda for Sustainable Development
UHC	Universal health coverage
UN	United Nations
UNDP	United Nations Development Programme
VPD	Vaccine-preventable disease
WHO	World Health Organization

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The European Health Forum Gastein (EHFG) continues its mission of creating a better and more sustainable future for health and societal well-being in Europe, bringing actors from all four EHFG pillars – public and private sectors, civil society and science and academia – to the table for frank dialogue and inspired co-creation.

“It is important that policymakers and stakeholders are ready to take disruptive action for the benefit of patients and health systems. This is why the EHFG 2019 challenged the pioneer spirit of the participants and encouraged them to form a community of healthy disruptors, to accelerate change, reform, and evolution.”

Last year we asked our delegates to consider bold political choices for Agenda 2030. And in 2019, around the theme ‘A Healthy Dose of Disruption? Transformative change for health and societal well-being’, the Forum delivered disruption in both form and content.

Disruption can be critical to precipitating necessary changes and requires robust leadership and courageous collaboration. Only with joint efforts and platforms for candid exchange can we harness positive disruption, within the delivery system of healthcare as well as in what is being delivered.

From 2nd to 4th October 2019, the EHFG called for solidarity, transparency, and courage in tackling health challenges at a time of new beginnings for Europe with the new European Commission and the recent nomination of a new WHO EURO Regional Director. In 2020 we will continue to explore the big issues in health, business and politics to advance human well-being and societal equity and stability, no matter how uncomfortable or controversial they may be.

I would like to take this opportunity to thank our partners and session organisers, as well as EHFG board and Advisory Committee members and the EHFG team for their support and contribution to this year’s conference. We hope that you will join us at the Forum’s next edition from 30th September to 2nd October 2020, and continue to be bold and disruptive when it comes to championing health and well-being in Europe.

Clemens Martin Auer
President, European Health Forum Gastein



European Health Forum Gastein

The European Health Forum Gastein (EHFG) is the leading annual health policy event in the European Union. With its wide-ranging three-day programme, the Forum offers an unparalleled platform for decision-makers in public health, healthcare, and beyond.

The European Health Forum Gastein was founded in 1998 with the aim of providing a candid, intersectoral and inclusive platform for discussion to stakeholders in the field of public health and healthcare.

Since then, the EHFG has developed into a key annual event reaching far beyond classic spheres of health policy, and bringing together politicians, senior decision-makers, representatives of interest groups, and experts from government and administration, business and industry, civil society and science and academia. These four groups of stakeholders with their perspectives constitute the four pillars of the European Health Forum Gastein, and the EHFG further

considers the vertical organisation of societies and the EU by integrating regional, national, European and international levels.

The Forum facilitates the exchange of views and experience amongst key actors and experts from EU Member States and the EEA countries, but also from the other countries of the WHO European Region. Launched with major financial support from the European Commission, subsequent events have grown with the continued and extended co-operation of EC services as well as many other European and international partners.

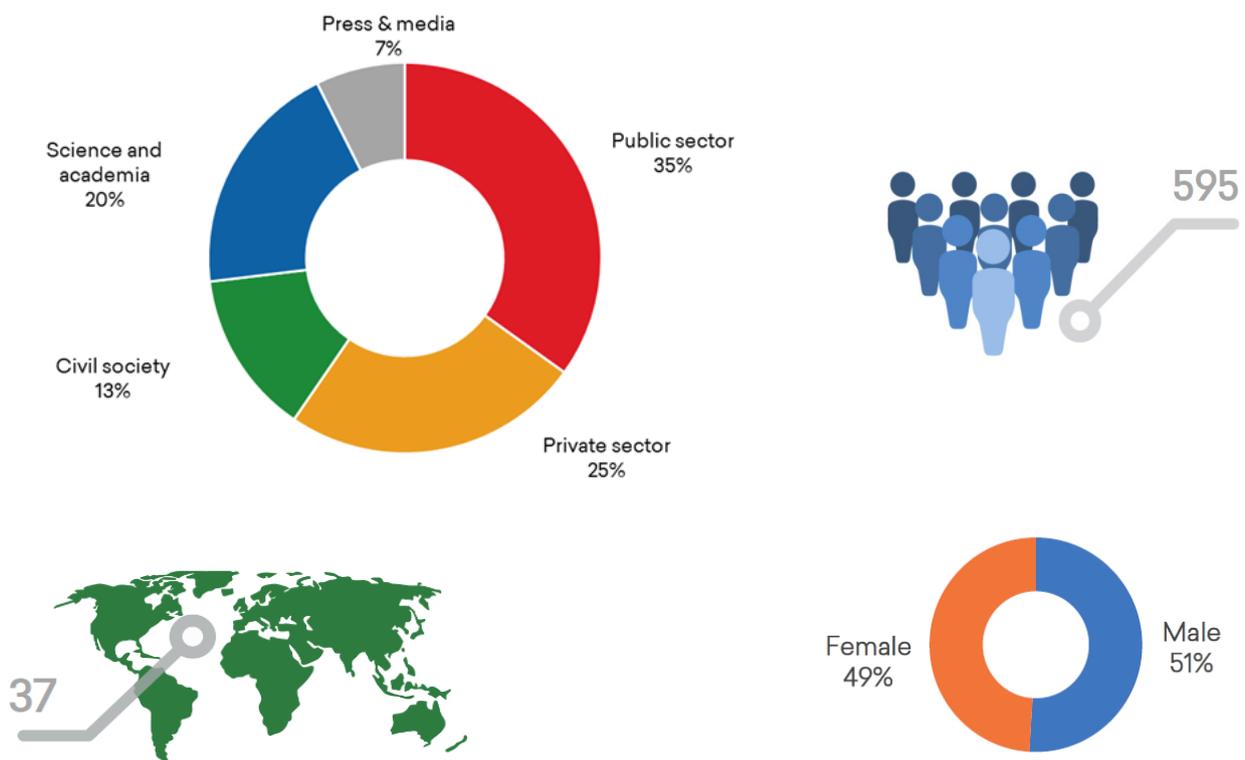




EHFG 2019 in numbers

Gastein brings together the worlds of politics, science and academia, the private sector, and civil society in a setting where everyone is equal. Around 600 leading experts participate in the annual conference - the unparalleled mix of participants is especially critical to the success of our event.

About our participants¹



¹ All numbers from the EHFG 2019 conference



Opening Plenary A healthy dose of disruption?



Organised by European Health Forum Gastein

The theme of the European Health Forum Gastein 2019 built on the big and bold thinking emphasised in 2018, highlighting the need for continued change and innovation in our approaches to improving health in Europe. ‘A healthy dose of disruption’ provided the framework for wide-ranging conference sessions seeking to disrupt the status quo in order to deliver better outcomes more sustainably. The engaging Opening Plenary addressed this theme in both form and content, ably moderated by Nick Fahy, Senior Researcher, Primary Health Sciences, University of Oxford. It was kicked off by Clemens Auer, President of the European Health Forum Gastein, on why there was a need for a healthy dose of disruption.

A call to action

A palpable sense of impatience – clearly reflected too among the speakers – was immediately established: we know what needs to change, we know many of the things that will deliver these changes, and yet we continue with ineffective actions. In part, this may be attributable to the complexity of our health systems, each comprised of almost innumerable independent

actors with their own aims and agendas. But awareness is not an excuse, and delegates were called upon by Clemens Auer to be “healthy disruptors; to accelerate change, reform, evolution.” Clearly, disruption is inherently challenging, and success is not guaranteed. But each disruption has its time: Auer referenced the Two Loops model of change (articulated by Margaret Wheatley, Deborah Frieze and others during their time at The Berkana Institute) which describes how as a dominant paradigm starts to decline, there is an opportunity for an alternative approach to emerge in its place. This new model is defined by trailblazers, facilitated through connections and network formation, and ultimately supported by others in critical roles. The opportunity presented at Gastein was to create a community of healthy disruptors to drive this agenda for better healthcare and health systems and improved health and wellbeing.

Disruption is here – for those who pursue it

Stephen Klasko, President, Thomas Jefferson University, Philadelphia, USA and CEO, Jefferson Health, provided a

compelling case that the need and opportunity for this new paradigm is now, describing myriad innovations at his own organisations as well as elsewhere whilst noting that the fundamentals of healthcare delivery have not changed in his 40 years of practice. Now, however, changing population needs and newly available technologies have driven a move from Jefferson Health towards 'healthcare with no fixed address' which enables greater access and efficiency for staff and patients. But these and other changes are only possible if the workforce is ready and able to change too, so Thomas Jefferson University have also reformed their medical education programme, focussing not just on admission grades and on recalling information, but on knowing what is important and meaningful to patients and on being able to most effectively use information. Klasko stated that we are rapidly entering a world where our performance is less dependent on what we can memorise but on whether we can ask the right questions. Alongside new approaches to the selection and training of staff, there is an obligation to teach our health professionals to be ready for any change that will happen in the coming decades; "any doctor that can be replaced by a computer, should be."

Reflections from disruptors

For the emerging community of disruptors at Gastein, some words of wisdom were provided by those who have been on a disruptive journey themselves, starting with a stark reminder by Rachel Melsom, Director UK and Europe, Tobacco Free Portfolios, that "if you are going to disrupt the norm, you need to understand that other people are not going to want you to do that." But while it can be a lonely journey, persistence in such efforts can quietly disrupt entire industries, such as with the shift brought about by Melsom and her colleagues, who in 2018 launched the Tobacco Free Finance Pledge at the UN: it now has 126 signatories whose combined assets in committed tobacco-free capital are worth USD \$9.8 trillion.

Ran Balicer, Chief Innovation Officer, Clalit and Founding Director, Clalit Research Institute, Israel, focussed minds on the transformation possible through digital tools, as distinct from the tools themselves. To be effective, we must focus on processes and how they may be supported by potentially disruptive technologies rather than on the technology itself: "If you take a broken process and digitise it, you have a costly broken digital process," he warned. Clearly technology is part of the future, but it does not determine it. He emphasised

that while digital health is our greatest hope for effective healthcare transformation, if we do not do things properly, we could make costly mistakes which will lead to over-diagnosis, the widening of health disparities and reductions in health system sustainability. Balicer advocated using digital tools more judiciously, such as moving from synchronic to asynchronous care, where patient and physician use digital tools to communicate rather than having to rely on face to face interactions. He also advocated a predictive, proactive population approach to change the current paradigm of healthcare, where interventions are made after finding the right patients at the right time. "Let's seriously reimagine the process of delivering care, and only then key in the technology," he concluded.

Some disruptions can be short and sharp and achieve longstanding impacts, such as in the vaccine contracting changes described by Paola Testori-Coggi, Former President, Committee for Price and Reimbursement, Italian Agency for Pharmaceuticals and Former Director-General, European Commission Directorate-General for Health and Food Safety. In this instance, a monopoly position in the market was disrupted in order to achieve a better balance between innovation and affordability. To do so required bravery and an understanding of the market as well as commitment and a sense of just cause. Finally, Jan de Maeseneer, Family Physician, Department of Public Health and Primary Care, Ghent University and Former Chairman, European Forum for Primary Care, gave an overview of all the disruptive changes in primary healthcare (PHC) for which he has advocated throughout his long and distinguished career. He discussed how he was involved in reforming undergraduate medical education to train a new type of health professional fit for the 21st century that required a skillset based on inter-disciplinary cooperation and teamwork, an understanding of the social determinants of health, and a community orientated approach. A new environment in which these health professions could effectively operate was also required, however, and de Maeseneer was involved in the creation of PHC zones in Flanders that were accountable for 100,000 people. His advice to future changemakers was to base their efforts on universal values (e.g. sustainability, equity and social justice, respect for autonomy and diversity) and have a clear vision and patience. He also advocated work to strengthen democracy in Europe, much greater investment in PHC and for Europe to urgently engage in a new dialogue with Africa around issues including



free trade, migration, climate change, and capacity building in health and education. Finally he reflected on the recent UN High Level Meeting on Universal Health Coverage (UHC) and stated that we have to look more broadly at people's needs in this context and consider multi-morbidity, mental health, social inequities, and the need for cognitive care amongst other things. Therefore we need to revisit and broaden the indicators in order to define a broader concept of UHC so that we end up with an integrated PHC system – and he called for a European initiative to provide guidance on how to really achieve this.

Environments ripe for disruption

After these spotlights on disruption, a panel discussion highlighted some considerations for innovation as well as areas where disruption is still needed. Chris Fearne, Deputy Prime Minister and Minister for Health, Malta, used the example of drug pricing to note that negotiation and compromise is typically more sustainable than coercion, but that there comes a point where disruption is also needed as a critical supporting factor – for example to enable true transparency in costs and pricing in order to counter pharmaceutical monopolies. Two critical requirements of policymakers and administrators to better support productive disruption were offered by Martin Seychell, Deputy Director-General, European Commission Directorate-General for Health and Food Safety: ensuring the regulatory framework is sufficiently flexible and responsive to foster innovation within agreed parameters, and enabling

sensible data sharing and use across relevant parties. These are two of the most challenging issues for policymakers in the healthcare sector, which lags behind other industries in these areas. Here a timely reminder came too, that innovations are not inherently disruptive, and may in fact simply reinforce the status quo. This thread, one running through several speakers' remarks, was strengthened here, encouraging deeper reflection than the simple conflation of technological innovation with disruption.

Appropriately, this was followed by Batool Al-Wahdani, Youth Advocate and Past President of the International Federation of Medical Students Associations, who offered an alternative perspective on what still requires disruption in the health sector. Al-Wahdani noted the frustration felt by many that while young people are consistently referred to as the leaders of tomorrow, too little tangible action takes place; the question is how to invest in young people now. To do this, young people need to be properly considered as stakeholders in our systems of operation, including through more effective support to equip medical students for the future. The current model of medical education is not fit for purpose (a point evidently also recognised at Thomas Jefferson University before implementing their new medical curriculum) and needs “not just disruption, but to be destroyed and rebuilt,” she emphasised. Finally, the audience were reminded that while the workforce is increasingly made up of women and people of colour, we have yet to see this reflected in leadership positions. It was an apposite point to end on with so many senior leaders from across the globe gathered together; perhaps the most effective route to improving our systems of care would be through disrupting the hierarchies we continue to operate within.

The opening plenary was concluded with the European Health Leadership Award, a new award to recognise exceptional leadership in improving health at the European level. This was awarded to the Tobacco Control Research Group at the University of Bath, in recognition of the impact their research has had on tobacco control policies across Europe.

Learn more

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Thursday Plenary The human touch in a digital world



Organised by the European Health Forum Gastein

There is nothing more disruptive in today's healthcare world than the digital transformation of our healthcare systems, a process which has the potential to reshape the relationship between patients, healthcare providers and health systems. What impact will digitalisation and the increased use of artificial intelligence (AI) in healthcare have on the human touch? Moderator Sue Saville opened the session with this challenge – is 'Dr Google' empowering patients or encouraging over-diagnosis and hypochondria? Are the days of 'doctor knows best' over? What are the challenges that we must acknowledge and overcome to ensure a focus on patients at the centre of healthcare in an increasingly digital world? Finding a balance between digital transformation and the potential benefits to population health while addressing some of the challenges such as safety, ethics, equity, and trust will be key.

Applying technology in the right ways to solve the right problems

In a keynote address, Hans Kluge, Director of the Division of Health Systems and Public Health at WHO Regional Office for Europe and the Regional Director-elect for WHO Europe, posed a rousing challenge to the audience by pleading that we should not sleep-walk into a digital future. Whilst

he acknowledged that the future of digital health was a priority for all, he outlined the importance of creating safe, affordable and inclusive digital health services, requiring the development of ethical frameworks and morally responsible policies that tackle the digital divide and leave no-one behind. Given the significant challenges to healthcare systems related to demographic change, workforce sustainability, personalised health services, and healthcare affordability, increasing digitalisation offers potential solutions but we need to be careful not to invest blindly, potentially exacerbating existing problems. We also need to be aware of the design and commercial motivations of any new digital technology and build a future based on social need instead of financial impact. This will require new models of governance, and the importance of robust leadership in advancing this equitable digital health landscape cannot be overlooked. Kluge concluded by arguing that no technology will ever replace the human touch, but it is human cooperation and partnership that will enable us to build the best digital future for all.

Human interaction in healthcare settings

A high value was placed on the importance of human interactions in healthcare, with a warning that we should be careful not to design the patient out of the system. Šarunas

Narbutas, President, Lithuanian Cancer Patient Coalition and Chairman, Youth Cancer Europe argued that face-to-face interactions with his doctor are very important for him, quoting a study which showed that 80% of young cancer activists preferred human to technological interaction. Indra Joshi, Digital Health and AI Clinical Lead, NHSX, England, echoed Narbutas' point, describing a UCLA study assessing apps for children in foster care with mental health problems: when asked about the best tool in the study the children overwhelmingly chose the time when a social worker would take them out for ice-cream. Digitalisation should be about empowering patients by ensuring that they have access to the necessary knowledge and information to have effective consultations, said Narbutas. Ran Balicer, Chief Innovation Officer, Clalit, and Founding Director, Clalit Research Institute, argued that there are some mundane and simple tasks that technological solutions could perform better than healthcare professionals, freeing up their time for other tasks.

Anna Stavdal, Past President of the World Organization of Family Doctors Europe (WONCA Europe) and President-elect of WONCA World, hoped that digital tools would free up time for greater human interaction, but questioned whether this is the current reality and worried about their potential to increase over-diagnosis. For some family doctors as little as a quarter of their allotted time with a patient is spent on face-to-face interaction, the rest being spent on increasingly complex digital tools and bureaucratic processes. Balicer emphasised that the medical community needs to take ownership of the digitalisation process, to ensure that we are not creating for the sake of it but instead developing solutions to problems. This is essential to avoid an epidemic of over-diagnosis and overtreatment in the near future if private interests keep developing more and more 'sensors'. We do not want to fall victim to 'sensoritis', the phenomenon of sensory overload of seemingly helpful solutions that actually cause more problems than they are solving. As Balicer eloquently put it, "it is time to infuse more science into this art."

Individual vs Population – who owns the data, and is ownership important?

Narbutas argued that the key issue is access to data and not just for the medical, academic, and policymaker communities. Patients should be entitled to access their own data and they should have ownership of this information. Experience matters and we should empower patients with the necessary tools to

make the most of the technological advances that already exist. Anna Stavdal and Indra Joshi raised questions about data ownership. Should we even use the term 'ownership' or is it now about the flow of data, who is controlling the data, who is processing the data? What is data and who owns the knowledge of a person's health? If data comes down to labels, two patients with the same diagnosis may be given the same label, but they often have two completely different experiences.

Continuity of care was a common discussion point. Stavdal argued that we need to be careful not to conflate longitudinal electronic medical records with continuity of care as personal continuity includes the silent knowledge held by an individual's physician. Some aspects of care may never make their way into an individual's medical record. This takes us back to the human jigsaw puzzle; are data comprised of the labels that professionals give to individuals or are data a combination of the individual's narrative and life journey? If it is the latter, no-one could possibly own this except the patient themselves, however there is arguably significant value in this mundane labelling of diagnoses at a population level.

Ran Balicer argued that we cannot truly provide population health without population level data. In his opinion we need to move away from an individual approach to proactive, productive data use on a massive scale. In Israel patients are being risk-scored using AI technology for their likelihood of developing kidney disease in five years; they are proactively approached with lifestyle interventions before they develop the disease. These technological advances have shown value to the public by making their journey through the healthcare system easier, thus gaining public support for such innovation. If we want to innovate on this scale it is imperative that we have the correct tools to do so – population level data are vital, whilst acknowledging other caveats such as privacy and data security. But do we place this data utility above the importance of an individual's 'story'?

Standards, frameworks and interoperability

Balicer emphasised that laying the right building blocks, such as comprehensive electronic care records and building interoperability into systems from an early stage, are essential. We do need common standards and frameworks, and importantly we need agreement on that amongst all stakeholders, said Indra Joshi. She defined two types of

digitalisation, 1) systems - doing things in a more digital way, and 2) therapeutics - treating people in a more technologically focused way. She emphasised that clear standards are required for both, and interoperability is essential. This point was supported by Marco Marsella, Head of the eHealth, Well-being, and Ageing Unit, European Commission Directorate-General for Communications Networks, Content and Technology, who argued that standards are vital to ensuring healthcare information can travel and be understood across borders. There is a need to build in mechanisms that enable data sharing, and as Joshi previously alluded, to ensure that we understand the same things in the same way. Interoperability is important on many different levels and we must reconcile not only the technical aspects of it but also the semantic, legal and organisational components of data sharing.

Algorithms are not impartial judges, just opinions embedded in code

A query was raised regarding unpacking algorithms and our understanding of what they actually mean. Indra Joshi clearly outlined the difference between explicit ability and interpretability; just because the former is possible doesn't mean the latter is definite. Marsella described a pilot project to build trustworthy AI through embedding ethical principles into their development to set the baseline for a trustworthy application. Ultimately, algorithms are not value-based; only human choices are value-based. Is it possible to build this into digital models - should we even try?

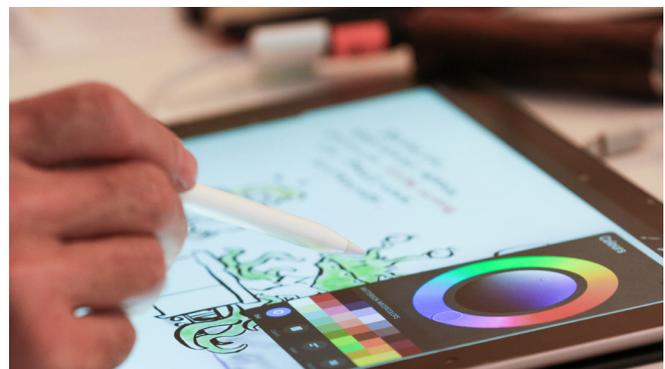
The limitless possibilities of a digital future

Joshi spoke about some of the potential applications in which digital technologies could play a future role: leaning over a cadaver in medical school could become an app-based experience; using AI to predict traffic light patterns could improve ambulance travel times to hospital; machine learning to interpret ultrasound images as point-of-case diagnostics, patients hacking their own wearable devices to improve device function. Narbutas reminded us that it's not just 'high tech' solutions, but also finding new ways to make 'old tech' work, with an example of mobile text messages being used to significantly improve patient knowledge, despite the technology being relatively 'outdated'.

Speakers and participants also discussed what exactly 'public health' means - is it giving information to patients, or ensuring that they make the decisions we want them to make?

Finally, how do we measure success in digitalisation? It must be about more than new innovative technologies, which alone do not necessarily bring about the changes needed. There was a consensus that solutions should be problem-driven - there is no point in creating new technology for the sake of it. Often the technology already exists.

We need to be issue-driven and use digitalisation to enhance the relationship and interaction between a patient and their healthcare professional. Is it possible to acknowledge the questions and concerns that increasing digitalisation raises whilst also being excited about emerging digital innovations? The speakers agreed that the duty of public health professionals is to ensure that digitalisation is safe, accessible, and affordable for all, and this requires international partnerships with an emphasis on equity and accessibility, while maintaining the human touch in healthcare.



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Closing Plenary

The global climate crisis - a public health emergency

Organised by European Health Forum Gastein



Clemens Martin Auer, EHFG President, opened the plenary by issuing a simple call to action for participants during his conference round-up: “Wherever you are, whoever you are, be part of this healthy community of disruptors!” If we do not take action, he warned, others will step into the vacuum, and precipitate destructive – not healthy – disruption. The topic of the final EHFG 2019 plenary was on disruption of a global and potentially catastrophic scale. Scientific research shows that global heating in the last century has pushed the Earth’s temperature to unprecedented levels, and the UN Intergovernmental Panel on Climate Change has warned we have just over a decade to limit this heating to a maximum of 1.5 degrees Celsius, beyond which hundreds of millions of people will be severely affected by extreme heat, drought, flooding and poverty. The Closing Plenary of EHFG 2019 therefore set out to discuss the climate crisis as the foremost public health emergency that the world is facing.

The disruptive tactic of civil disobedience

A musical “boomwhackers” interlude set the scene perfectly for a subsequent intervention from Stella Indira Auer, a young student representing Extinction Rebellion Austria. She highlighted the urgency of the climate crisis and the overwhelming evidence of the

causes and effects of global heating, and asked everyone to pause for a moment and consider if they were doing all that was in their power to act on the climate and ecological crisis. Lamenting that we should have listened and already acted on the warnings from scientists one or two decades ago, she remarked: “Our fight has just started.” Auer described how in recent decades civil society organisations have signed petitions, lobbied governments and organised marches and demonstrations to raise awareness and spur action on the climate crisis, but to little avail. Now organisations such as Extinction Rebellion have adopted the tactic of civil disobedience, because it is non-violent and seems to be more effective than traditional forms of advocacy. She urged plenary attendees to join a rebellion and demand that governments act on the climate crisis.

Growing recognition of the climate emergency

In the subsequent panel discussion moderated by journalist Anya Sitaram, Rockhopper Media, Stella Auer was joined by three discussants: Veronica Manfredi, Director of Quality of Life, European Commission Directorate-General for Environment; Brigitte Zarfl, Minister of Labour, Social Affairs, Health and Consumer Protection, Austria, and Stefi Barna, Co-Director of the Sustainable Healthcare Education Networks, as well as Sir

Andy Haines, Professor of Environmental Change and Public Health, London School of Hygiene and Tropical Medicine, who participated via pre-recorded videos. Initially the participants discussed the recent growth of international recognition on climate-related matters and the corresponding outcome of recent events: just the previous week, leaders at the United Nations Climate Action Summit had demonstrated recognition that the pace of climate action must be rapidly accelerated. 65 countries committed to cut greenhouse gas emissions to net zero by 2050, while 70 countries announced they will either boost their national action plans by 2020 or have started the process of doing so. A “European Green Deal” is forthcoming under EC President-elect Ursula von der Leyen, who has stated that she wants Europe to become the world’s first climate neutral continent. These international commitments are a first positive step, however critics suggest it is too little, too late and/or that commitments are not ambitious enough and we need to be aiming for net zero by 2030 or even earlier.

Implications of the climate crisis for human health

Andy Haines presented the main implications of the climate crisis on human health. There are the direct effects (increased mortality, reduced labour productivity, impact of extreme events such as floods, droughts and other catastrophes on human health); indirect effects mediated through natural systems (changing patterns of vector borne diseases like Malaria, Dengue and Zika, water-related diseases and undernutrition) and climate effects mediated through social and economic systems (an additional 100 million people could be pushed into poverty in the absence of decisive action on climate change, and it will affect migration patterns and lead to an increased risk of conflict). Haines stated that the real concern is that we may be moving towards catastrophic effects post-2050 if we exceed the temperature threshold of 1.5 degrees Celsius.

What can governments and international organisations do?

In this context then, what can governments do to protect public health from the impact of the climate crisis? Brigitte Zarfl cited an example of a heat telephone line in Austria which had to be activated during recent summers to protect vulnerable groups. In Austria roughly 7% of carbon dioxide emissions can be attributed to the health sector, so Zarfl championed the need for more effective ways to deliver

health to the population (reducing the distance they have to travel to healthcare facilities, for example) and more efficient and effective use of pharmaceuticals to reduce waste. This led to a challenge: the idea of climate-smart health initiatives. Globally the health sector contributes over 4% of global greenhouse emissions – from the energy requirements of healthcare facilities to carbon created by procurement. Stefi Barna advocated for a triple bottom line: climate smart initiatives that improve quality of care for patients, reduce costs, and reduce greenhouse gases, stating that a side effect was also an improvement to staff morale. “Public health is the speciality that has the skills to bring forward change,” she emphasised, citing its qualities and capacities such as system thinking, multidisciplinary approaches, evidence-based practice, data analysis and ensuring equity at its heart.

The EC has successfully managed to decouple sustainable growth and a reduction in emissions and show how both are possible. It also has a zero pollution ambition for Europe, said Veronica Manfredi, discussing why it was important to tackle the root causes of pollution in tandem with those of the climate crisis: it is largely the same economic sectors (energy, travel and transport) responsible for both and well-targeted actions will lead to benefits across multiple sectors. Being constructively critical, she outlined how the EC has a zero-tolerance approach to infringements on air quality standards, however these standards need to be urgently updated in line with the latest WHO recommendations. “We have a lot of relevant legislation,” she acknowledged, “however we need better political will to implement it.” All the panelists agreed that more radical action and measures were now required, and that the use of civil disobedience was justified to drive this issue higher up political agendas, given that other methods had tried and failed. Indeed the next 15 months are critical to achieving political consensus on how to tackle this emergency: before we reach the tipping-points of no return, the global community must agree to implement radical changes in order to avert disaster. “2050 is too late,” implored Stella Auer, urging for a step-change in the global response: “to a great extent speed is going to determine how this will all play out.”

Fireside Chat

Ilona Kickbush, Professor and Director, Global Health Centre, Graduate Institute of International and Development Studies, Geneva, took the stage to moderate a “fireside

chat” with Piroska Östlin, Acting Regional Director, WHO Regional Office for Europe and Vytenis Andriukaitis European Commissioner for Health and Food Safety. In light of the topic of the preceding panel discussion, both Andriukaitis and Östlin discussed how the Paris Climate Agreement was probably the most important public health agreement of this century. Nevertheless, it was recognised that globally we are experiencing two public health crises, not only the climate crisis but also a crisis of access to healthcare, which 50% of the global population still lack. In his own inimitable, passionate style, the Commissioner discussed the paradigm changes needed to implement the SDGs, and implored his successor to involve more actors from other sectors in discussions on how to reach these important milestones, the deadline for which is only 11 years away. He also issued young people with a call to action to tackle syndemia such as the behavioural and commercial determinants of health and the climate crisis. Piroska Östlin reinforced the message that the agendas of the climate crisis and universal health coverage (UHC) support each other and have interlinked priorities. She reflected on when she felt we worked together most successfully most successful, suggesting this was at a sub-national and inter-sectoral level, for example through networks such as the WHO Healthy Cities or Regions for Health Networks. In these structures it is easier to open-up about common problems and solutions across different policy areas and these efforts should be scaled-up, she thought. Andriukaitis agreed: “We need to raise our voices now and unite progressive agendas in every country, every city, every community, every village,” he said.

Be passionate about healthy disruption for change!

The plenary gave an insight into the sense of urgency needed to scale-up the interlinked challenges of delivering UHC and actions to tackle the climate emergency. It highlighted the passion that everyone needs to have as part of this community of healthy disruptors to bring about change, especially where there are threats to joint action between countries and organisations, to multilateralism itself and to the scientific community which too often comes under attack, whether from anti-vaxxers or climate-change deniers, and where we must learn to be more courageous and forceful in our response. It also gave a sense of the crucial importance of the political dimension in bringing forward change. Ilona Kickbusch advocated that all of us need to reflect this passion and commitment for health in whatever we do. Lastly, the

session highlighted the responsibility across the whole of society and all sectors (regardless of the traditional roles played thus far) in tackling a wide variety of global challenges, but in particular elevating a successful response to avoid climate and ecological breakdown and societal collapse within our lifetime. We clearly need a healthy dose of disruption if we are to act effectively. “If we are to overcome the many challenges society faces, we need to see much more honesty from people who govern and much more disruption in terms of how we think about health. This is a joint responsibility for all of us – policymakers, industry, NGOs, patients - on the things that really matter,” stated Vytenis Andriukaitis.

Addressing vaccine hesitancy through the EHFG Hackathon 2019

The final element of the plenary was the voting for the winner of the EHFG’s second Hackathon, jointly organised with EIT Health, followed by the Award Ceremony. 35 participants from 20 European countries were divided into seven teams and given 48 hours to develop innovative solutions to the problem of vaccine hesitancy. Three finalists pitched their projects to the plenary participants: 1) VAX-ins - a digital solution to empower “vaccine-hesitant” parents to make an informed decision about vaccinating their children; 2) #immYOUrise - a digital reminder system for health authorities, insurance companies, and industry partners, that targets the unconcerned and hesitant populations to increase vaccination coverage, using electronic vaccination records together with an automated personalised reminder system and 3) VAXOn - using big data analytics to identify anti-vaxxer groups and provide reliable analysis of their activities for governments and NGOs in order to develop timely and effective vaccine campaigns and in so doing decrease vaccine hesitancy. Securing 47% of the plenary audience vote, VAXOn won the EHFG 2019 Hackathon and the prize money of €25,000.



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Data for safer care

Digital solutions & surveillance systems for patient safety

Organised by Health First Europe and European Network for Safer Healthcare (ENSH), sponsored by Beckton, Dickinson and Company



Patient safety in terms of healthcare-associated infections (HAI) and antimicrobial resistance (AMR) is a global and timeless problem. This workshop addressed the main barriers that key stakeholders encounter, but also untapped opportunities where digital solutions and surveillance systems can be used to make hospitals safer for the patient. "It is unacceptable that as a patient, you leave the hospital sicker than you entered it", stressed Fernando Simón, Director, Centro Coordinador de Alertas y Emergencias Sanitarias, Ministry of Health, Spain.

8.9 million annual HAI in the EU

The scene was set by Andrea Ammon, Director, European Centre for Disease Prevention and Control (ECDC), giving a brief overview of the EU-wide surveillance landscape on HAI and AMR, including some tangible recommendations on next steps. In the EU, there is an estimated 8.9 million HAIs per year, of which 25-35% are assumed to be preventable. Routine surveillance systems for AMR (EARS-Net), antimicrobial consumption (ESAC-Net) and HAI (HAI-Net) are in place, but the data collection once a year limits their timeliness. The representative of the Joint Action on Antimicrobial Resistance and Healthcare-Associated Infections (EU-JAMRAI) and the Institute of Biomedicine of Seville, German Penlava, agreed that "once-a-year" is not enough. Therefore, a pilot project of a quarterly data collection scheme is currently in place, with 15 collaborators from 10 countries providing, ideally, data on 41 different indicators every three months (29 on antimicrobial consumption and 12 on AMR).

How do we use this data on an organisational level?

A session participant from Denmark introduced an already existing real-time surveillance system for HAI, with publicly available results. However, interventions based on data at local or organisational level are known to be difficult to implement, while point prevalence surveys (PPS) engage the local healthcare staff more intensely. There seems to be more motivation through dedicated staff and allocated

time for the investigation and implementation of the PPS. Routine surveillance data communication does not achieve the same level of involvement and reactions - yet. Federico Lega, President, European Health Management Association (EHMA), identified the issue of both organisations and people being naturally inclined to be "problem-driven" and not "solution-oriented": They get jolted into action only through a negative event. Fiona Garín McDonagh, Senior Director, Strategic Marketing Europe, Beckton, Dickinson and Company, also argued that while there are limited funds and a plethora of competing priorities in healthcare, some of the resource constraints applicable to HAI and patient safety are part of a broader theme throughout the healthcare system, like for example staff turnover, staff shortages or laboratory capacity. Improving these factors would affect the healthcare system as a whole and the beneficial effect would be multifaceted. Furthermore, the so-called surveillance bias - "if you look more, you will find more" - was identified as a frequent barrier to motivating institutions to implement more rigorous surveillance systems. Simón highlighted that to fight this mindset we need to emphasise that HAI and AMR are not isolated, one-hospital problems, but a pan-European, multidisciplinary challenge that can only be solved by collecting, exchanging and learning from data.

Another discussion point emerging from the audience was the General Data Protection Regulation (GDPR) and the corresponding restrictions on data collection and usage. Ammon argued that the GDPR should not serve as a shield and block further development of data collection and exchange. Rather, technical solutions to limit the misuse of personal data should be explored and an open dialogue kept with data protection officials in order to overcome this hurdle. The GDPR also clearly gives the opportunity to Member States to link data for specific purposes - important for instance in research and public health - as well as to develop the appropriate legislation to ensure this data linkage is secure.

Digitalisation, patient safety and cybersecurity

All panellists agreed that a big obstacle for data exchange and collation is the available infrastructure, there being a high diversity in the way data is collected and stored locally and exchanged nationally and internationally. Digitalisation and automation could introduce innovation, reduce the workload of surveillance and improve the timeliness and usefulness of surveillance systems as outbreak detection and intervention tools. This is feasible for AMR and antibiotic consumption data because these are numerical, while for HAI there is more assessment that is clinical, involves patient contact and requires fine-tuning of algorithms. Paul Garassus, President, European Union of Private Hospitals, introduced a broader facet of patient safety– cyber security. As we progress in the digitalisation of our healthcare systems, a major issue to be considered is cyber security, as ransomware could immobilise whole hospitals and thereby threaten patient safety. Nevertheless, without a better communication strategy of the outcomes and usage of the information at hand, even a fully automated and digitalised system will not lead to improved patient safety.

Benchmarking a no-blame-culture

Benchmarking was mentioned by all panellists as a possible way forward. However, in order to make benchmarking a success, there is a need for a larger cultural shift and the promotion of a no-blame-culture. One model was presented by Sinikka Salo, Leader of Change, Permanent Secretary's Cabinet, Ministry of Social Affairs and Health, Finland. Salo explained that 20 years ago, Finland implemented a web-based tool that is now widely used in private and public practice to report safety incidents anonymously and voluntarily. Another approach, as brought forward by Lega, would be to actively acknowledge and celebrate successes throughout the organisation and put more focus on indicators that point to learning opportunities, and not only indicators used for accountability. Neda Milevska, Board Member, International Alliance of Patients' Organizations, emphasised the central role of patients that has not been exploited for the purpose of increasing patient safety. Personal health data in the smartphone era is already used as an economic asset. Why can we not learn from the commercial sector, use these experiences and employ the same technology to turn data into a health asset? We need to educate and empower patients more so that they can choose and "vote-with-their-feet", serve as a quality assurance and act as an external benchmarking force.

The way forward: aligned data handling and greater patient involvement

In order to use data for safer care more efficiently, all panellists unanimously agreed that a harmonisation of data collection needs to happen. Some interventions that could increase patient safety and reduce HAI are cheaper, like alcohol hand disinfectants at bed side, while others are more expensive, like single bedrooms, increased staff to patient ratio, increased time dedicated to antimicrobial stewardship or increased lab capacity. However, the latter will have a broader influence on the healthcare sector as a whole, and not only on reducing HAI. There is an intrinsic human opposition to the benchmarking process, which is rarely seen as a tool for self-improvement, but rather feared as a threat of punishment. Therefore, a blame-free culture is crucial and needs to be fostered more within the healthcare system. There is a need to raise awareness of the problem on every level, both within individual organisations – from the patient-contact to the managerial board – and across whole countries, regions and on EU level. HAIs have been around since the dawn of hospitals and AMR since we started using antibiotics. To succeed in tackling these challenges, we need to involve patients at the centre of our discussions and use their voice for a stronger political and institutional commitment.



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The digital future of healthcare

Using data to FutureProof health systems

Organised by Roche



A packed room and tables with colourful Lego blocks. We are invited by Jörg-Michael Rupp, Director of Pharma International at Roche and Health Futurist Bogi Eliason, of the Copenhagen Institute for Future Studies (Cifs), to dream without boundaries of a future-proof digital health care. Entering an intellectual Disneyland if you will - with the aim of building upon a blueprint of improving digitalised healthcare.

Be futurist

First and foremost, we need to work together towards our digital future. No company or person can do this alone. Päivi Sillanaukee, Director General at the Ministry of Social Affairs and Health, Finland, points out that joining forces and creating common roadmaps will help set conditions for better data use, including advancing a paradigm shift towards humans and well-being at the centre, as also advocated in the Economy of Well-being approach championed during the current Finnish presidency of the Council of the European Union. It is however hard to get brains together and move things collectively forward. In order to generate combined ideas without constraint, Rupp and Eliason strongly believe an engagement approach such as used in this session can help move things along.

Digitalisation and personalisation increasingly shape every aspect of healthcare. To deal with the new paradigm that is coming, Eliason introduces the FutureProof Index that is launched at the session. Cifs developed this index measuring

healthcare sustainability in terms of access, health status innovation, quality and resilience. Eliason explains the FutureProof Index is developed with the intention to look at combined data and inspire improvement.

In need of change

Within this vision, the need to adapt our healthcare systems to the future is a clear focus. To succeed, we cannot avoid asking ourselves: are our health system priorities still based on yesterday's systems? In order to provoke the audience to start thinking like futurists, Eliason adds that we have been trying to make changes too slowly to something that is already in constant flux. So far, policy changes have led to incremental change, not the disruption we need. To help frame our dreams and discussions, Eliason proposes ten things in need of change in health systems for a bright digital future.

1. From disease to health focus
2. From incident to lifespan focus
3. From quantity of treatment to outcome & quality of life
4. From input to outcome reimbursement
5. From silos to open data
6. From clinical to health-related data
7. Bridge system and individual data
8. From ignorance to the right to know
9. Decrease lifespan disease burden
10. Work in ecosystems

How to proceed? To start dreaming, leading subject experts



share their insights.

Who are the disruptors? Players or the system?

What does one answer when asked about the digital transformation of the future? Indra Joshi, Head of Digital Health and AI at NHSx England offers a keeping-it-simple perspective. NHSx focuses among other things on personalised healthcare, a nice frame for the participants to keep in mind when dreaming about the future. An example Indra is passionate about is the development of an NHS app based on first addressing things people most immediately need, such as booking an appointment and access to records, but also things that do not often get discussed, such as end-of-life decisions.

Fear around privacy considerations can be considered a barrier for digital healthcare. Both Joshi and Eliason stress that ethics are a big consideration when it comes to futureproofing healthcare. Ethics in data, ethics in ownership - just think about the recent livestreamed videos broadcasting a violent tragedy out of New Zealand. Building frameworks and code of conducts are pivotal in this sense. It is however pointed out that ethical constraints change over time - considering for example the change in discussions around in-vitro conception from a horror-scenario spin on test-tube Eugenics to the right of choice for everyone to procreation and their own children.

Mary Harney, as Former Minister of Health, Ireland, and a self-described recovering politician, reminds us of the unheard data possibilities. The digital revolution offers fantastic opportunities. Yet, Harney points out systems are not being organised around technology. In that context, technology is merely seen as an enabler. If you impose technology on a broken system, technology can actually add to your problems. However, technologies can play a major role in delivering the right care in the right place at the right time, Harney stresses, if we can surpass our current constraints.

"If I asked my customers what they wanted, they would have said faster horses". We don't want digital healthcare to be developing faster horses, but by quoting Henry Ford, Usman Khan, Executive Director, European Patient's Forum (EPF), reminds us of the risk of focussing only on improving existing tools and systems. On that note, in the field of cross border health care, Sillanaukee brings the example of Finland and Estonia to our minds. Together, these countries are

trailblazers in developing information sharing with over 4000 prescriptions being filled cross-border.

The switch of focus from barriers to solutions is nicely provided by Maria Pilar Aguar Fernandez, European Commission (EC). The EC, Aguar stresses, is taking important steps to further action in improving conditions around digital healthcare, but cannot do this alone - a call for action for the audience. As Joshi, Aguar also keeps things simple for us by using the ABCD of AI, BigData, Cloud and DigiCare, together the four current strains of focus for the EC.

The way forward

Dreaming leads to solutions - seven facilitators summarise the results of the interactive table group discussions among participants.

1. For the first group, Khan identifies barriers in health literacy and access to data as the most pressing to address to **effect person and patient empowerment**. The group suggests health literacy education in schools to address the former, and health data systems development - putting in place the right data architecture! - as pivotal to the latter.
2. On the topic of **genomics**, Layla McCay, International Director, NHS Confederation, adds that the improvement of health literacy can also assist in navigating tough ethical question around **genomics**. Elevating the question of genetic testing to a more vigorous public debate, as well as supporting healthcare staff to guide meaningful consent decisions, may help people to understand the issue and make informed choices.
3. Discussing **data sharing and governance**, Sillanaukee relates that the group identified a need for (i) comprehensive data structures and interoperability, (ii) processes and protocols for easy access, (iii) licensing to test innovations, (iv) setting the right incentives and (v) an open dialogue on ethics to build trust around data sharing - and stresses that for all of these, government backing and political will are essential.
4. Harney explains that **proactive instead of reactive care** is the future, and improvement of knowledge through awareness campaigns in schools and for (health) professionals are still needed, as well as financial incentives that go towards prevention and promotion more than treatment. The group highlights examples

such as a 50/50 funding model in the Finnish town Oulu as well as ringfencing investments towards technology and interoperable systems as suitable tools.

5. For the fifth table group, Sarah Buckley, Public Affairs Lead for I8/Global at Roche, introduces policy recommendations around **tech and AI**. On one hand, codes of conduct on ethics in AI are deemed necessary, which along with better education for (health) professionals could perhaps also be set by professional bodies. More specific ways to determine outcome quality standards are also mentioned - when it comes to choosing and using particular technologies and tools for our data handling, such as Blockchain.
6. On **connecting health data across Europe**, the sixth table group as summarised by Rupp posits that a technical and semantic interoperability present main barriers. To tackle these, the group identifies first and foremost a need for leadership, but also for common standards – even if they sometimes mean compromising for more advanced technology users.
7. Picking up the leadership theme, Sarunas Narbutas, Chairman of Youth Cancer Europe, addresses **political**

will in prevention and early detection. The group identifies a clear distribution of responsibility and roles as paramount – and a need to reverse engineering rhetoric that really brings across the value of prevention also to finance ministries and budget holders in their language.

Collaboration and commitment

In order to transition towards personalised and preventive health, collaboration between a wide range of actors and commitment to a vision for health seem to be the two crucial factors. With the seven focal points emerging from the session, a start is made towards an 'ideal' digital health strategy that can inform a policy blueprint for the digital future of healthcare.

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When epidemiology meets Big Data Challenges and opportunities of an inevitable encounter



Organised by the European Centre for Disease Prevention and Control (ECDC)

In this interactive session organised by the European Centre for Disease Prevention and Control (ECDC), key experts and EHFG participants discussed the value and potential pitfalls of the ever-increasing influence of Big Data in public health services and research across Europe, in particular as it can be applied to the field of epidemiology.

Participants were prompted to embrace critical thinking of what the future holds in terms of the interaction of data and public health in the next ten years - and consider how to take advantage of technological advances and reconcile challenges presented to traditional approaches and techniques used in infectious disease prevention and control today.

A digital path for public health surveillance

Kicking off the session, the moderator **Andrea Ammon**, Director, ECDC, and **Martin Seychell**, Deputy Director-General, Directorate-General for Health and Food Safety (DG SANTE), European Commission, emphasised that a well-digitalised

system has the potential to improve access, continuity and quality of care for patients across many different health care settings. At the same time, hurdles need to be overcome in the methodological arena, where adapting the principles currently used in data collection and analysis to the realities of Big Data is not always simple or straightforward. In the realm of legal and ethical considerations, aspects such as intellectual property and data protection remain challenging.

As compared to other sectors, Seychell added, in the health field we may still only be scratching the surface of what is possible with the high-quality data we collect. Data sharing between Member States and the use of electronic records has great potential to improve surveillance and analysis, as well as access to personal health records - also when seeking unplanned care in another Member State - and the speed of outbreak responses.

Collaboration in the sharing of not only data but methods, scripts, and algorithms is crucial to achieving tangible benefits

through Big Data. Several Member States – Finland, Estonia and Croatia for e-prescriptions, Luxembourg, Czech Republic and Croatia, with more to join them soon, for electronic patient summaries – have recently been trailblazers in data sharing among European health systems, with significant results. There is far still to go, and EU instruments such as the eHealth Digital Service Infrastructure (eHDSI) can help to advance the collaboration. By 2022, Seychell concluded, the forthcoming Commission hopes to have fostered an exchange of electronic patient data among 22 MS, with all remaining MS following suit soon after – creating a European health data space with data privacy and security always foremost in mind.

In an open conversation with the panel, participants explored challenges to data security posed by likely upcoming jumps in technology such as quantum computing - but also opined that we should not be too afraid of them: many challenges posed by leaps in technological advancement also contain the seed of their own solution. Other participants stressed that we need to remain critical on what benefits new significant data sources offer to epidemiological research, and make sure that 'traditional' concepts, such as design bias and causality, are adequately reflected in how big data is analysed. Public and private sector must work together meaningfully to meet these challenges, participants agreed.

Philip Abdelmalik, Team Lead, Health Emergencies Programme, World Health Organization, reminded us that some form of data has always been at the core of public health surveillance efforts. What is important about Big Data is not the data itself, but how we use it and the insights that we gain from it. Open source information not initially intended for public health surveillance purposes – online media articles, government websites, social media, open source publications, and even radio broadcasts in areas with poor internet coverage – can be an excellent tool for event-based surveillance, anomaly detection and forecasting if contextualised against other available data sources. WHO is currently leading the Epidemic Intelligence from Open Sources Initiative (EIOS), which brings together new and existing systems into one collaborative web-based platform scanning hundreds of thousands of open source articles and reports every day, helping to identify unexpected or unusual information and enabling cross-disciplinary experts to share crucial content across the network.

Tyra Grove, Head of Department, Infectious Disease Epidemiology & Prevention, Statens Serum Institut, Denmark, shared experiences with the digital surveillance of influenza, a disease with a high financial burden annually EU-wide despite available preventive measures. Grove highlighted that by linking different data sources – such as microbiology databases, vaccination registers, patient registers, administrative information like death registers - to the information on patients tested for an infectious disease like influenza, a comprehensive picture of trends, severity, risk groups and estimated vaccine effectiveness can be created. However, while the benefits such as real-time, cost-efficient information are evident, Grove added that technical challenges of digital data-driven systems remain, and we must 'learn to embrace imperfect data' while putting resources towards continuously improving data capture and management.

Big Data for healthy habits

Shifting focus from surveillance to behavioural change, **Maurice Kelly**, Client Director for Quality Improvement, Health Service Executive (HSE), Ireland, stressed that public health actors must use social media and the analysis of trend and data harvested from it as tools to counter the strong presence of fake health news on the most popular platforms. In Ireland, social media campaigns by anti-vaccination groups, lacking evidence but appealing to emotion, accompanied a drastic drop in HPV vaccination uptake among the population a few years ago. However, building alliances with patients and combining accurate data with the stories and lived experiences of real people in public health campaigns can help to take back the narrative - as demonstrated by a significant rise in vaccination uptake following a HSE video campaign reacting to the drop in vaccination numbers.

Sean Howell, CEO of the LGBT Foundation and Co-Founder of Hornet, addressed how the voluntary and community-based collection of health data through social media networks can help to target information and interventions to at-risk populations and inform public health policy. In the gay social network Hornet, participants elect to share their HIV status and whether they are currently taking Pre-exposure prophylaxis (PrEP). Together with the ECDC, data from Hornet users was analysed to determine patterns of and potential for PrEP use in Europe – much more quickly and cost-effectively than could have been possible through a traditional epidemiological study. Participants agreed that such public and private sector

collaborations on Big Data can be crucial to speed up progress in the area of infectious disease, but data protection and a focus on improved outcomes for patients must be critically evaluated and ensured.

Indra Joshi, Head of Digital Health and AI at NHSx England, underlined that the next ten years will be a defining decade in exploring how data can be used to refine and improve health services and patient outcomes. Involving people outside of traditional health information organisations and structures will be crucial, participants agreed – as well as involving health practitioners, especially those in primary healthcare. Improving interoperability as well as building trust are key, Joshi added. To this end, the use of Big Data in public health needs to be underpinned by robust safeguards and ethical principles.

People will not change their behaviour just because data exists - health professionals, advocates, and public and private actors in health alike need to figure out how to best translate Big Data and advances in health technology into impact and improved outcomes.

The road ahead

Data is arguably the most valuable resource in the world today, but in the field of health, we may not yet be using it to its full potential. We need to stop talking about Big Data in the future sense and start harnessing its potential today - involving healthcare professionals, championing cross-sectoral collaboration and constantly improving data collection, interoperability and management, while never forgetting the human factor, and embedding ethics by design.

Asked for their top two keywords that came to mind at the end of the session, it is not surprising then that the audience put forward 'opportunity' and 'ethics': two concepts that must remain complementary as we move into a decade full of technological possibilities and innovation in public health and epidemiology.

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Horizon Europe Strategic priorities in European health research

Organised by the Directorate-General for Research and Innovation (DG RTD), European Commission, and the European Health Forum Gastein



Horizon Europe (HE) is the successor to Horizon 2020 – the future framework programme of the European Union (EU) on research and innovation (R&I) for 2021-2027. This ambitious programme has an estimated €100 billion budget and is the EU's leading initiative to support R&I from concept to market, complementing national and regional funding. HE has been designed to support partnerships between EU countries, the private sector, foundations and other stakeholders, and aims to deliver on global challenges and industrial modernisation through concerted R&I efforts.

Shaping Horizon Europe

The session, moderated by Nick Fahy, Senior Researcher, Primary Health Sciences, University of Oxford, offered the participants a real opportunity to contribute to the European research agenda and identify key priorities for HE. Maria Pilar Aguar Fernández, Head of Unit, Innovative tools, technologies and concepts in health research, European Commission Directorate General for Research and Innovation (DG RTD), introduced HE, and explained how through a modern consultation process, DG RTD is involving critical stakeholders, using a novel design exercise, while ensuring the framework is aligned with the Sustainable Development Goals (SDGs).

HE aims to create synergies in Europe to promote inter and intradisciplinary research networks. For the Health Cluster, a total of 6 key areas of have been identified, namely: health throughout the life course; environmental and social health determinants; NCDs and rare diseases; infectious diseases; healthcare systems, and tools, technologies and digital solutions for health and care. Aguar Fernández encouraged every expert to submit their ideas and recommendations through the online consultation system, highlighting that HE is a great opportunity for EU R&I to better tackle society and citizens' needs in a meaningful way.

During the subsequent panel, representatives from industry, government and civil society provided their views on how HE should be shaped.

Intersectoral collaboration

Martina Glibber, Director of External Relations, Institut Merieux, emphasised that different sectors ought to work together and join forces to develop innovative approaches and define novel strategies and business models, with citizens at the centre. A holistic approach is needed to cover the whole spectrum of healthcare, starting from health promotion and prevention,

through to early disease identification and diagnostics, then treatment and home and palliative care. A cross-sectoral lens should also be a focus, considering for example human and animal health and digital technologies to name but a few. She thought that ensuring patients have earlier and quicker access to innovative products and services, including soft tools such as personalised nutrition and stress management, was also important to ensure better health outcomes.

Ensuring societal impact

Fiona Godfrey, Secretary General, European Public Health Alliance (EPHA), opened her comments by questioning whether citizens had seen a significant impact from the €80 billion that had been spent on Horizon 2020. She stressed that this must change with HE: it represents a great opportunity to transparently include civil society from the outset and better ensure societal impact. She exhorted the need to create a roadmap to improve cross-sectoral citizen engagement (through civil society forums for example) and create a meaningful role for all citizens in co-designing and creating research programmes, while ensuring clarity over what research is being done, why it is being done and who it is being done for. She added that the mission concept of HE is very exciting and presents us with a whole new set of criteria for doing research, linking research to citizens, embedding the idea of transparency and democracy in research and building and creating the European project. On the latter she emphasised the current major challenges faced by society in Europe (such as the climate crisis, rising far right populist movements attacking public health, health and economic challenges): HE must help us address these challenges, it must be accountable and transparent and its results must be accessible for citizens, she exhorted.

Openness and transparency

Liisa-Maria Voipio-Pulkki, Chief Medical Officer and Director General, Ministry of Social Affairs and Health, Finland echoed Godfrey's comments about the mission focus of HE and stated that they should be high ambition and high profile initiatives – the Boards have already been appointed and they should visit MS for exchanges. She also discussed the ever-present research-policy gap: high quality research will be of limited value if it doesn't speak to policymakers or healthcare providers in a meaningful way – one benefit from HE could be that we better learn how to reach common goals and speak the same language.

Bart Vermeulen, Deputy Chief of Cabinet of the Belgium Minister of Social Affairs and Public Health, Asylum and Migration, also welcomed the investment of public funding into R&I to provide citizens with a better quality of life, but like Godfrey he stressed that this huge investment and undertaking needed to be underpinned by openness and transparency. He advocated that HE needs to be focused on the needs (and particularly the unmet needs) of citizens and patients in MS, and therefore should support specific challenges including reimbursement mechanisms; health workforce issues; multi-disciplinary approaches to healthcare, and we should use the many tools that already exist to guide HE in this direction.

Participants weigh in

Participants then discussed their own ideas for shaping HE. These included the imperative to take into account the real needs of European citizens; to reduce current the emphasis on technology; to be more transparent and meaningfully inclusive; that HE should offer a platform to share all the research outputs produced, even those offering negative or non-significant results; to align mission and research objectives with the SDGs; and the need for a multidisciplinary approach to fight climate change.

Shaping the future of research

This workshop represented a unique opportunity to discuss with diverse stakeholders the way HE should be shaped while gaining views and insights about the process. Aguar Fernández assured that key discussion outcomes will be taken into consideration. It was agreed that there exists a real need to translate evidence into policy, and HE should offer a transversal, innovative and integrated response to address the coming challenges of the 21st Century.

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CAR-T: The evolution of a revolution?

Organised by Novartis

As a leading cause of death and suffering, the treatment of cancer has been the focus of extensive research and has mobilised an extraordinary amount of resources, both public and private. Recently, the harnessing of the immune system to target cancer cells directly has yielded great benefit to patients suffering from the disease. Immune checkpoint inhibitors (drugs that release the brakes cancer cells put on the immune system to prevent their destruction) have become standard practice in the oncology clinic. However, treatments that use genetically manipulated immune cells from the patient to destroy the cancer cells, despite their great promise, are still administered in a restricted group of tertiary healthcare centres of high-income countries.

Focused on Chimeric Antigen Receptor (CAR)-T cell therapies for cancer, this session was moderated by Duane Schulthess, Managing Director, Vital Transformation, and enabled a broad-level multidisciplinary dialogue. Not only were the key basic principles of this new therapeutic option presented but concerns about access and potential inequalities in care discussed, and the implications for several health system building blocks examined.

The revolution in cancer care

Setting the stage for the discussion, Antonia Muller, Senior Consultant, Division of Haematology, Zurich University

Hospital, described CAR-T as a revolutionary cellular therapy that allows individualised recognition of tumour cells and their management by modifying immune cells. In brief, the patient's T lymphocytes are genetically engineered to produce chimeric antigen receptors (CARs) on their surface, so that when the cells are reinfused into the patient the new receptors enable them to recognise a chosen tumour type. When used to tackle haematologic malignancies with a hitherto sombre prognosis (mainly acute lymphoblastic leukaemia and large B cell lymphoma), these modified T cells can significantly improve patient survival rates.

Inherent to its scientific underpinnings, this is not a "one size fits all" therapeutic approach, but an approach that requires patient-specific T cells and recognition markers that are particular to the tumour ailing the patient. The highly individualised nature of these therapies renders its scaling difficult. So far, the production of CAR-T cells has involved the shipping of blood samples from worldwide healthcare centres to production units almost exclusively located in the United States of America. Unfortunately, these treatments are not free of adverse side effects, but their profile is different and the impact on a patient's quality of life less severe when compared to chemotherapy and stem cell transplant-based alternatives.

Universal access is far from guaranteed

Marius Geanta, President, Centre for Innovation in Medicine (InoMed), Romania, explained how the access model is being built in Romania and the strategy being used to persuade the Romanian government of the importance of CAR-T cell therapies. He highlighted the need for new pricing strategies when the shift from long-term therapies to one-time treatments (like CAR-T cells) eventually occurs. The hope is to achieve this through concerted action which includes, amongst other activities, creating a media environment, agenda-setting, and targeted interventions such as the creation of a Personalised Health Committee.

Should CAR-T cells fulfil their promise, lack of access will provoke inequities that should undoubtedly be prevented. A discussion panel between Antonella Cardone, Director, European Patient Coalition; Šarunas Narbutas, President, Lithuanian Cancer Patient Coalition and Chairman, Youth Cancer Europe; and Zack Pemberton-Whiteley, Patient Advocacy Director, Acute Leukaemia Advocates Network, addressed the question of CAR-T cell access and possible solutions to mitigate inequities.

In the European context, wider cross-border collaboration is needed. CAR-T cell therapy requires expertise that can only be acquired through specialisation, and specialisation requires the volume and centralisation of care into highly differentiated centres. Nevertheless, centralisation could reduce access. A trade-off between centralisation and access needs to be acknowledged in order to allow a constructive discussion on the mechanisms to address it. In EU Member States (MS), a greater focus on CAR-T cells by the European Reference Networks could help prevent inequities in care.

Furthermore, Narbutas highlighted the importance of controlling the hype surrounding CAR-T cell therapy in order to prevent false hope in ineligible populations. Geanta agreed and emphasised that when dealing with highly personalised therapies such as CAR-T which are only available to a small cohort of patients, personalised communication is crucial to ensure the correct information is circulated. Pemberton-Whiteley warned of the need for further studies on the quality of life experienced by patients that have undergone CAR-T cell treatment, and the importance of developing infrastructure to register patient-reported outcomes in a systematic way.

The system-wide implications of CAR-T cell therapies

Thomas Szucs, Professor of Pharmaceutical Medicine, University of Basel, stated that we are now in the personalised precision medicine era in which evidence-based medicine has become a “lame duck”. This uncharted era in medicine poses new problems for drug development requiring updated models adapted to this reality. For instance, CAR-T cells, due to their high one-off costs, challenge current drug reimbursement schemes. This fact is particularly relevant for Bismarckian health systems, where users can quickly change insurer. In these systems, the costs are supported by a single insurer even if the user subsequently changes health insurance provider. One of the proposed resolutions would be the use of a blockchain solution that would help transfer the costs of expensive treatments to a second insurer in such cases. For the moment, CAR-T cells are only approved for relatively rare cancers. These orphan indications have implications for product development by the pharmaceutical industry.

Emanuele Ostuni, Head of Cell and Gene Therapy, Oncology Region Europe, Novartis, explained how the company, despite facing considerable challenges, continued its investment in treatments for rare cancers, particularly in the paediatric setting. Overcoming these barriers implies the optimisation of digital health records allowing the follow up of real-world outcomes and new clinical trial designs. Contrary to the current trial designs that use a frequentist approach, new studies will need to use Bayesian statistical methods that can greatly reduce the required number of participating patients.

Where to next?

As with all revolutionary technologies, CAR-T cells will have health system-wide implications requiring a thorough analysis by all stakeholders concerned - the pharmaceutical industry, regulatory bodies, scientists, patients and healthcare professionals, and academia. An issue likely to attract great scrutiny is fair pricing. While not addressed in-depth during this session, it is important to devise new strategies to balance the financial incentives of the pharmaceutical industry and the public sector-funded research on which their drug development is often based. Inherent to their disruptive nature, we are still in the infancy of the discussion on how to offer equal access to CAR-T cell therapies in a way that does not put an additional strain on limited national healthcare budgets.



AI: It's not (just) about the technology!

New organisational models and skills for care providers and healthcare professionals

Organised by EIT Health



EIT Health is supported by the EIT
a body of the European Union

Over the past decade, Artificial Intelligence (AI) has seen an enormous rise in popularity due to significant advances in its effectiveness and use. Intense debate has surrounded AI and its implications for the future of healthcare. As the discussion continues, one thing is becoming increasingly clear: in order to have a positive impact on health outcomes for patients and citizens, we need to move on from our current discussions of the technology, to outlining crucial organisational changes for healthcare providers and systems, as well as addressing the skillsets required by future healthcare professionals to work successfully with AI. This session brought forward the vision and concerns of different stakeholders currently involved in this transition.

A slow transition

The popular discourse surrounding the use of AI in healthcare is often concerned with the technology itself rather than the ways in which national and regional health systems should transform their organisations to truly benefit from AI. While AI is expected to tackle many of the challenges currently faced by our health systems, healthcare transformation has failed

to keep pace with the rapid progress of medical technology. This transition is slowed down by strict regulations, resistance of healthcare stakeholders to change, and ignoring the importance of cultural changes and the human factor in an increasingly technological world. Jorge Fernández, Director of Innovation, EIT Health, highlighted this issue and suggested that disruption is needed to change the mechanics of healthcare. Moreover, he emphasised that to successfully incorporate AI into our health systems, we need to ensure that healthcare professionals are digitally capable of tackling this changing landscape. Quoting Beth Comstock, Vice President of General Electric, he described how currently “We’re caught inbetween the structures of the future which are still self-assembling and the structures of the past which are disassembled.”

Clinical implementation of AI-enabled technologies

Although very powerful, deep learning applications can be unpredictable when dealing with new situations, stated Steven Petit, Medical Physicist and Assistant Professor, Erasmus University Medical Centre. He argued that in order

to successfully implement AI into our health systems, we need to teach our healthcare professionals to manage its unpredictability. Indeed, healthcare professionals need to be trained to understand how the technology works and they need to be able to validate the data and detect potential errors. Healthcare workers, however, are not always so excited about adopting new technologies, sometimes with good reason. The emergence of AI has been considered a potential threat to professional recognition, jobs, and other incentives for which professionals enter the industry. There is no doubt technology will change how healthcare professionals work: whilst some tasks will disappear others will be added to the work routine, and smart doctors will use AI to their advantage. Dominik Pförringer, Medical Specialist for Orthopaedics and Trauma Surgery, University Hospital Munich Rechts der Isar, pointed out that diagnosing and treating patients is not a linear process, it requires creativity and problem-solving skills that algorithms and robots cannot replicate. No two patients are the same, there will always be varying factors. Thus, no case is the same; each will require attention, to some degree, from a human physician.

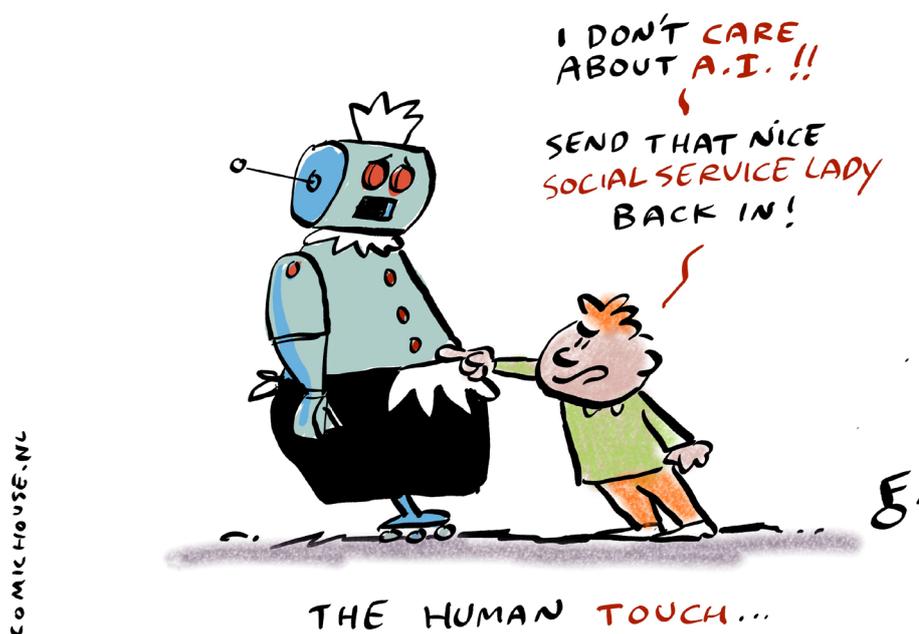
Creation of new roles with a tech focus

Indeed, there are certain jobs that will gradually disappear as AI-enabled technologies become more common in the health sector. However, there are also professions that cannot be replaced by technology. For instance, nurses who work

very closely with patients will become even more important in shaping patient experiences and ensuring the continuity of human care under a novel system. AI will also create the need for numerous new roles and specialties with a focus on technology, as Ursula Mühle, Director of Education, EIT Health, highlighted, the demand for data scientists and change managers will exponentially rise in the coming years. AI will also affect the day-to-day operations of many specialties (e.g. oncology, ophthalmology and radiology) making it possible for healthcare professionals to work more efficiently, improve the quality of care, and spend more time with their patients. Referring to findings from the Topol review, Mühle explained how currently, between 15 and 70 per cent of a clinician's working time is spent on administrative tasks (Health Education England, 2019). If these processes become automated there is a huge opportunity to improve the doctor-patient relationship. Indeed, there are several examples of AI being used to complement the skills of healthcare professionals, illustrating a new partnership between humans and machines in healthcare.

Content-based to experience-based education

Despite the need for a digitally capable health workforce to optimise the many opportunities offered by AI and digital health in general, widespread changes in recruitment and training are not yet occurring. Participants agreed that health professionals often lack the skills they need to understand



and appraise digital technologies and that they need to be trained to use them effectively. This will help tackle existing user fears and enable them to work effectively in a hitherto unfamiliar environment. Medical students are presently being taught according to out-of-date standards, a shift in learning is crucial, and new approaches need to be applied to modern medical education, preferably through a shift from content-based to an experience-based education. Healthcare professionals should be encouraged to travel and learn from others, allowing new solutions and visions to emerge. However, we should not only train our medical students but train our current workforce, including managers, to ensure there is a greater understanding of how these changes are likely to impact their work. Healthcare professionals, across the board, must be given an understanding of what technology can and cannot do. Understanding generates trust and with more understanding, more trust will follow. The understanding that new digital technologies can improve healthcare and the ability to select the right technology is a skill that every future healthcare professional should possess in order to exploit the advantages of the forthcoming digital future.

Multi-disciplinary approaches are the key to success

The session also highlighted another key issue: new systems should be developed to be user-friendly and hence, they should be created by technologists who work together with healthcare professionals and patients. Many different technologies are already used in healthcare settings, but they are not properly integrated into the system or are completely unrelated to the systems already in place, creating additional

burdens on healthcare workers and undermining patient experience. Thus, communication and collaboration between different stakeholders is essential during digital transition. As Pfürringer emphasised, we need cooperation and co-creation. The current practice of working in silos is not sustainable. Multidisciplinary teams are the key to success.

A little less conversation, a little more action!

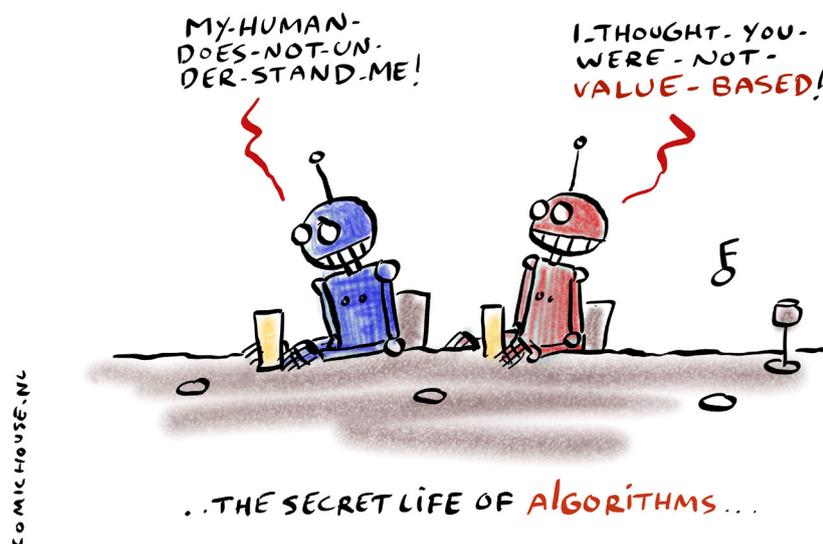
AI has the potential to support healthcare professionals in providing effective, high-quality healthcare for all patients. However, the use of technology only leads to better health outcomes if the related cultural and organisational challenges are acknowledged. Clinical teams must adapt to change and embrace the technology in order to make the most of it in healthcare structures. A digitally capable health workforce is one of the most important enabling factors underpinning success in this transformation and hence, we need to make sure that our current and future healthcare professionals are ready for this challenge.

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Steering, not rowing! Strengthening governance for health system performance

Organised by the Austrian Ministry of Labour, Social Affairs, Health and Consumer Protection and the European Observatory on Health Systems and Policies

 **Bundesministerium**
Arbeit, Soziales, Gesundheit
und Konsumentenschutz

European
Observatory
on Health Systems and Policies
a partnership hosted by WHO

The governance challenge

Governance, defined as “how we make and implement collective decisions,” was the focus of this lively and impassioned workshop. Participants and speakers came together to discuss how to strengthen governance and share country perspectives on the challenges of implementing health system reform and strengthening the governance systems that guide reform.

National health reform case studies

There are many challenges in reforming complex, dynamic health systems, and it is helpful to share experiences and learn from each other. Clemens Auer, President, European Health Forum Gastein, and an architect of the recent Austrian health reforms, identified the Austrian constitution as one barrier to reform. However rather than using this as an excuse for inaction, policymakers agreed a set of shared legally-binding targets which were used to persuade decision-makers that the current system wasn't working. This reframed issues around health system financing and primary healthcare reform from political to ethical questions and persuaded some to voluntarily give up their sovereign right to facilitate change. Noora Heinonen, Ministerial Adviser, Department for

Insurance and Social Security, Ministry of Social Affairs and Health, Finland spoke of the multiple attempts to reform the Finnish health system: “successful failures” that have provided opportunities to learn from their challenges and build on their successes. For example, they have learned to adopt a staged approach rather than trying to reform everything at once. Laura Casey, Health Systems and Structures Unit, Department of Health, Ireland, discussed the ambitious ‘Slaintecare’ ten-year health and social care reform programme. Reforms were multi-faceted, including a population-based approach, integration, capacity-expansion and structural changes. Christoph Schwierz, Deputy Head of Unit Labour Market, Health and Social Services, Structural Reform Support Service, European Commission (EC), spoke about the EC’s mandate to bring technical expertise to Member State (MS) to support and expedite structural reform in the health sector. MS are required to request this expert input, as there must be country ownership of the reform.

Steering, not rowing

In the 1990s, Osbourne & Gaebler argued in their book ‘Reinventing Government’, that “the job of government is to steer, not to row the boat. Delivering services is rowing,

and government is not good at rowing.” In other words, governments should set the strategic direction and vision, whilst giving others responsibility over managing and delivering services. Is this the most effective way to govern? Scott Greer, Professor of Health Management & Policy, University of Michigan and European Observatory on Health Systems and Policies, argued that you can’t steer without rowing, or row without steering. Irrespective of how a system is organised, effective governance requires alignment between those who steer and those who row. Christoph Schwierz, in describing the EC’s role in supporting national health systems, demonstrated how their process is to support the rowing whilst national governments provide the steer.

Dimensions of governance and the TAPIC framework

Greer argued that governance is about solving the problems society wants you to solve, and offered a set of questions as a guiding framework. Firstly, it is necessary to ask: “is it a governance problem at all?” Sometimes it is rather about insufficient resources or a bad policy idea. Assuming it is a governance problem, the second question to ask is “within which domain of the TAPIC framework does it fall?”

Once the governance dimension has been established, an appropriate tool can be used to address the specific governance issue identified. Finally, it is important to ask what can be learned for future policymaking. Rather than hiding failures and challenges, it is important to see them as opportunities to learn in order to improve policy going forwards.

Governance opportunities and challenges

Transparency (T) in decision making and prioritisation were seen as critical to effective policy reform; for example, a transparent selection process for EC support to MS health reforms. Multiple lines of Accountability (A) can cause confusion and tensions, for example in the UK context where health professionals are accountable to their NHS hospital who must enforce entitlement regulations but also accountable to their professional and ethical obligations to help anyone in need. Continued stakeholder buy-in is crucial, and the Dutch had a good example of Participation (P) where stakeholders are asked to answer a range of policy questions and decision-making takes a bottom-up approach. Trust was seen as a key element to Integrity (I) and strengthening governance. Policy capacity (C) in Ireland was a challenge and they identified a need to bolster resources to allow for reform while maintaining normal business within the ministry and executive and meeting ongoing need.

Lessons learned for good governance

Health system reform involves many governance challenges, and there are examples of (un)successful reform attempts across Europe. However, we can learn from these; persisting because as Clemens Auer stated: “if we don’t find solutions for the people, we are betraying the people.” If we work together to break the problems down into smaller pieces and reflect perhaps by using the TAPIC framework, we can identify where more effort and optimisation is required and bring about successful future health reforms across European countries.

T	TRANSPARENCY	Making clear decisions, their grounds and the decision-makers
A	ACCOUNTABILITY	Ensuring that anybody who acts must account for their actions
P	PARTICIPATION	Ensuring that people affected by a decision can express their views in a way that ensures they are heard
I	INTEGRITY	A system in which organisations and jobs have clear definitions, and procedures, such as hiring and contracting, are regularised and clear
C	CAPACITY	The ability to develop policy that is aligned with resources in pursuit of goals

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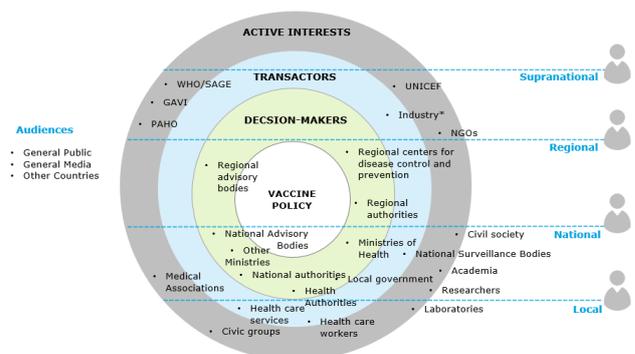
Vaccine ecosystem health check Identifying the components and experiencing the complexities

Organised by MSD and Sanofi



Vaccination is one of the most successful and cost-effective public health measures existing. It currently prevents 2-3 million deaths a year, and a further 1.5 million could be avoided if global coverage of vaccinations improved. Notwithstanding the clear benefits, several European countries are currently facing unprecedented outbreaks of vaccine-preventable diseases due to insufficient vaccination coverage rates. A leading cause of these low rates is vaccine hesitancy, the reluctance or refusal to vaccinate despite the availability of vaccines, which has also been listed by the WHO among the [ten threats to global health](#) in 2019. This suboptimal performance of a prevention tool that should be well established, especially in developed countries, is forcing governments and public health experts to further reflect on how to best ensure an improvement in vaccination coverage rates.

multitude of actors with varying roles and levels of involvement in each of the steps on the way from vaccine development to the administration of vaccines to patients. The figure below gives an overview of supranational institutions, national governments, regional authorities, industry, academia and civil society, and their respective functions within the system.



The vaccine ecosystem: a multitude of stakeholders interacting at multiple levels

The vaccine ecosystem is complex and composed of a

The session was moderated by Natasha Azzopardi-Muscat, Consultant, Public Health Medicine, Directorate for Health Information and Research, Malta and President, European Public Health Association (EUPHA), and featured a wide range of expert input to cater for the complex nature of the system, addressing numerous key challenges as well as possible solutions. Among these were the need for increased involvement of adequately trained healthcare professionals, improved access to vaccines and vaccine-related information, threats posed and opportunities provided by social media, the fragility and interdependence of the ecosystem, and the importance and intricacy of innovation, supply and demand.

Panos Kanavos, Associate Professor of International Health Policy, Department of Health Policy, London School of Economics and Political Science (LSE), and Deputy Director, LSE Health, opened the discussion with an overview of the core components of the current vaccine ecosystem, outlining both its challenges and opportunities. Among the issues Kanavos highlighted were supply and distribution asymmetries, demographics and appropriate targeting, pricing and procurement, and the alleged inadequacy of current innovation systems. Potential solutions to some of the questions raised included stronger financing of research and development (R&D), empowering non-EU manufacturers, an increased number of effective suppliers, a balanced inclusion of both public and private perspectives, and political prioritisation.

Kanavos called for stronger and resilient immunisation programmes and improved information collection as a cornerstone for shaping future-proof vaccine markets. A coordinated effort is fundamental to making this happen, for example through a European platform for all stakeholders, mitigating silos and facilitating a better mutual understanding of each other's concerns and positions.

Breaking the silos

The ensuing panel discussion continued where Kanavos had left off: each of the panellists addressed challenges and potential solutions from their own point of view. Among other things, a number of key initiatives launched at European level, such as the European Commission Coalition on Vaccination, were introduced. Despite these being recognised as valuable contributions to facilitating stakeholder engagement, participants highlighted a persisting failure to acknowledge

the complex and multidisciplinary nature of the vaccine ecosystem. Adrian Pana, Health Policy Analyst, Founder and CEO of the Center for Health Outcomes and Evaluation, and former Secretary of State, Ministry of Health, Romania, illustrated this concern by saying that we are "... still viewing the vaccine ecosystem in black and white. We should look at it in full colour 8K to appreciate both its complexity and challenges."

The central role of healthcare professionals in bringing vaccines and vaccine information closer to the patient, for example through a more prominent role of pharmacists, was then also discussed. Antonio Gaudio, Secretary General, Active Citizenship Network, brought the citizens' perspective to the debate, with strong statements on the importance of putting people at the centre of the ecosystem, and promoting initiatives and policies opening gates for better access to vaccines and a peer-to-peer approach, reverting the often overused and ineffective top-down approach.

Alexander Kort, SVP Corporate Development, Themis Bioscience GmbH, highlighted the importance of innovation in vaccines as a vital way forward to ensure sustainability of the vaccine ecosystem, and emphasised how vaccine development and production can be even more complex than that of standard pharmaceuticals.

Together, speakers and session participants then interactively explored the multitude of views and concerns arising in the vaccines ecosystem by engaging in a simulation exercise involving different stakeholder groups. With participants putting on different "hats" with specific objectives to deliver and having to convince other stakeholders of their specific actions, it became evident that all forces at play within this ecosystem, from coverage rates, to access, to supply and affordability, are highly dependent on each other's support, with actions having direct impact on other drivers, especially in the situation of limited resources that characterise our health systems. With vaccines being the most successful public health measure to date, this is an important take-home message: it is crucial for all actors in the vaccine ecosystem to engage and align in order to ensure its sustainability and resilience.

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Facts. Figures! Fiction? How disruptive can missing health information be?

Organised by Gesundheit Österreich GmbH, Sciensano and InfAct, the Joint Action on Health Information

Gesundheit Österreich
GmbH

sciensano



There is no doubt that those from prior eras, if able to view our world as it is today, would be amazed by the sheer volume of information at our fingertips and its global reach. However, would they be impressed by its quality, the governance guiding its production and dissemination, and the way in which it is used by individuals and organisations?

At a time when the international health community is facing a host of pressing challenges, such as climate change and the global epidemic of NCDs, access to quality data to underpin interventions is crucial. However, we are currently facing an additional challenge regarding exactly this: the proliferation of the phenomenon commonly known as 'fake news'. While fake news is not strictly a contemporary issue, having existed since the advent of the printing press, never before has such rapid spread and wide reach of disinformation been possible. The digitalisation of our lives and the tailoring of messages based on the profiling of individuals using their online footprint exacerbate the impact of fake news. This is further compounded by the growing use of fake news by political leaders and others in positions of power.

What is 'fake news'?

Martin McKee, Professor of European Public Health, London School of Hygiene and Tropical Medicine, introduced the concept of fake news and the threat it poses to our ability to build public and political support for policies that promote health. He warned against blindly using the term 'fake news' as a catch-all phrase, used to refer to anything from satire to harmful untruths spread by political campaigns, as this renders the term of little use and vulnerable to manipulation and misinterpretation.

Instead, McKee advocated for a systematic approach to conceptualising potentially harmful information (Box 1), highlighting the importance of remembering that actors spreading such information can be driven by a variety of

motivations. For example, there can be a host of reasons for spreading anti-vaccine information – from concerned parents genuinely misunderstanding the evidence to trolls, bots, and content polluters attempting to fuel discord.

Box 1

MISINFORMATION: false or misleading information where there is no intent to deceive

DISINFORMATION: information purposely created to deceive people

FAKE NEWS: false information, fabricated and spread in a way that explicitly mimics news and media content

The crux of the problem is that many people may be vulnerable to all these forms of false information. The public often holds incorrect views on fundamental issues, and individuals are targeted with messages tailored to further strengthen such pre-existing views. These false messages capitalise on cognitive biases (e.g. disconfirmation, confirmation or attitude bias), which can further entrench members of the public in their false beliefs.

The power to disinform

The session moderator, Claudia Hahl, Head of International Affairs and Consultancy and coordinating engagement in the Joint Action on Health Information (InfAct) at Gesundheit Österreich GmbH (GÖG), Austria, tested the attendees' ability to critically evaluate information with a set of three true or false statements:

- Electronic cigarettes have been shown to be 95% safer than conventional ones.
- The increase in child obesity is because children spend all day on their iPads and watching television.
- People who are very ambitious and highly driven are at greater risk of having a heart attack.

All of these statements are false, and, as McKee pointed out, they were all proactively pushed by certain actors, mostly commercial, in order to boost their interests – often with the

use of poor science. This illustrates the importance of power in dominating the information landscape, also in regard to disinformation and fake news: It is about who has the power to (1) control information and how it is interpreted, (2) own and shape the message, and (3) decide who sees what information and when.

Exposing the problem

Guest speakers were then invited to provide recent examples of the importance of data and health information. Paola Testori-Coggi, Former Director-General, European Commission Directorate-General for Health and Food Safety (DG SANTE), discussed the worsening situation surrounding vaccine hesitancy and refusal in Italy, including a widespread misunderstanding of the health benefits and risks of vaccination and an active anti-vaccination movement spreading misinformation and disinformation, sometimes for ideological reasons. In response, the Italian government implemented a law requiring 10 vaccines before school entry for children aged 0-6 years and a fine for parents of unvaccinated children aged 7-16 years.

Christoph Thalheim, Secretary General, European Multiple Sclerosis Platform, brought another example by introducing the problem of health policy decisions being informed by false or incomplete evidence. He touched on both the Thalidomide scandal and care pathways for multiple sclerosis that lack evidence-base or overlook the need for a continued collection of evidence to enhance care.

Panos Kanavos, Associate Professor of International Health Policy, London School of Economics and Political Science (LSE) and Deputy Director, LSE Health, talked about data manipulation in the context of the US attempts to address

medicine price rises. Kanavos led a report warning against the recommended steps, but the report was misrepresented to make it seem the LSE had endorsed the proposed solutions.

Finally, Hanna Tolonen, Research Manager and member of the InfAct Steering Group from side of the National Institute for Health and Welfare (THL), Finland, highlighted the inconsistencies that exist across health datasets and how this can produce profoundly different interpretations when setting public health priorities, leading to confusion and inaction. Initiatives such as InfAct can help establish standardised, high-quality data sources across Europe in the future.

Several additional points were put forward by the audience and discussed by the panellists: the importance of moving beyond a 'more data is the answer' mentality and focusing on quality and robust research methods instead, the necessity to focus on reaching and sampling underrepresented and vulnerable groups, the need to acknowledge that the usefulness of data is a function of equity and power as not everyone is equipped with the skills to use it, and the ability to identify and counter "massaging" of evidence.

Rising to the challenge

Information, data and technology are necessary tools for delivering quality health and healthcare. However, when used inappropriately, of poor quality, or driven by vested interests, they can cause profound harm. We need to counter the rise of harmful information and fill the gap when safe and effective information is lacking or intentionally absent from the public debate. We must expose the harms, redress power imbalances, and protect information at all stages: collection, production, interpretation, and dissemination.



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Health workforce disruption Effectiveness and implementation of skill-mix innovations

Organised by the Health Foundation and the European Observatory on Health Systems and Policies



Innovation in healthcare is happening not only with the introduction of technology and Artificial Intelligence (AI), but as this workshop demonstrated – through health workforce disruption. The many challenges and opportunities faced by the healthcare workforce in Europe and beyond has led to innovation in how healthcare teams operate, including through skill-mix. Although often beneficial for patient outcomes, such innovations in healthcare can be met with resistance and lead to unintended consequences if implemented with insufficient support.

The many faces of workforce disruption and skill-mix

Skill-mix can involve expanding the roles and skills of the existing workforce (e.g. increasing responsibilities of pharmacists), adding new experts to the team (e.g. dietitians) or involving patients. The expanding role and responsibilities of the nursing profession was the most commonly discussed example of skill-mix and disruption in this session, with a particular focus on their ability to prescribe medication. As Jim Buchan, Senior Advisor, The Health Foundation, stated, “The ability to prescribe by non-physicians is a critical enabler and disrupter that will overnight create new demand and provide the stimulus for new supply.” There have been many cases of workforce disruption at both local and national levels, especially in primary and long-term care. Claudia Maier,

Researcher, Technical University Berlin, presented findings from an overview of systematic reviews on skill-mix. Between 2010-2018 there were over 188 systematic reviews in the field, including 20 Cochrane reviews and 47 meta-analyses. Crucially, skill-mix in healthcare teams was shown to have a positive impact on many health indicators, including diet, physical activity, and post-partum outcomes.

During an interactive element of the session, attendees were encouraged to share examples of skill-mix innovations that have been implemented in their home countries, or to identify gaps where skill-mix would be beneficial. Examples presented included the establishment of cross-border ambulance services between the Netherlands and Germany; the introduction of pharmacy assistants in the Netherlands; dental hygienists receiving autonomy in Belgium; enhancing the education received by nurses in Austria and Hungary; new nurse practitioners doing a better job than GPs of appropriately prescribing antibiotics in Scotland; dentists and physiotherapists educating patients on smoking cessation in the UK, and nurses taking on more responsibilities and autonomy in underserved rural areas of Hungary.

Drivers of workforce disruption

There are a number of scenarios that can facilitate workforce disruption. One such example, discussed by Francois

Schellevis, Senior Researcher, Netherlands Institute for Health Services Research, was the 2015 national reform of long-term outpatient care in the Netherlands. The reform, almost overnight, led to the decentralisation of planning and financing to municipalities, forcing local councils to develop new procurement systems, conduct needs assessment through 'kitchen table dialogues', and establish interdisciplinary care teams. Other drivers included the emergence of new healthcare specialists, such as medical professionals trained for war zones, who return home equipped with unique skills, and the health workforce brain drain which is often facilitated by free movement within the European Union. Nevertheless, all countries are faced with an ageing workforce and increasing demands on their healthcare systems.

Implementing and managing workforce disruption can be challenging

There are many risks and barriers to skill-mix and workforce disruption. While it was emphasised that a 'one size fits all' approach will not suffice, it is clear that successful workforce disruption and skill-mix requires a number of elements, including incentives and fiscal solutions, supportive legislature, appropriate training models, and perhaps even lobbying. The example, shared by Schellevis, on the changes made to long-term care planning and provision in the Netherlands, demonstrated that without appropriate support and adequate frameworks in place, local councils may struggle to implement and sustain new arrangements for long-term care. Jim Buchan noted strong opposition from medical associations was a key challenge in expanding the role and responsibilities of the nursing profession. This was also cited as a contributing factor

as to why Australia lags behind the United States and United Kingdom in enabling nurses to prescribe, an issue which has been exacerbating the already poor access to healthcare in remote areas of the country.

As a prerequisite to implementation, the role of education will become increasingly important, and further research will need to be carried out in order to gauge the minimum training required for these expanding roles and the team members involved. The risk of fragmentation in care leading to lower patient satisfaction is a further unintended consequence of inappropriate skill-mix and workforce innovation that needs managing. Indeed, both the discussion in this session, and the considerable body of literature to date omitted the perspective of the patient. Closing the session, Buchan pointed to "The political cost of disruption in healthcare," but session moderator, Anita Charlesworth, Director of Research and Economics, The Health Foundation, emphasised that there is "A value to being brave," as new roles can quickly be embraced and their positive impact evidenced. Schellevis concluded – we should "Never waste a good disruption!" There is ample evidence to suggest that local innovation can become national disruption and lead to healthcare transformation if enough knowledge exchange and support surround it.

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A European Cancer Plan Make it disruptive!



Organised by European Cancer Organisation (ECCO), European Federation of Pharmaceutical Industries & Associations (EFPIA), European Cancer Patient Coalition (ECPC) and The Organisation of European Cancer Institutes (OECI)

Cancer is both a health and social issue, and a holistic approach is needed. This session aimed to provide an overview of challenges in cancer care in the European Union (EU) and trigger a discussion about the prospect of a European Cancer Plan to improve the record on cancer. Panellists included academics, healthcare professionals, patients, policymakers and pharmaceutical industry representatives.

Nils Wilking, Associate Professor, Institute of Health Economics, Karolinska Institute, opened the debate by presenting the scale of the challenge. Every year, there are almost four million new cases of cancer in Europe. More people are being diagnosed with cancer, but screening, prevention, diagnosis, and treatments are helping patients live longer and with a better quality of life. Cancer related deaths have fallen by 20% over the past 20 years. However, data included in the forthcoming “Comparator Report on Cancer in Europe 2019 – Disease Burden, Costs and Access to Medicines”, showed that cancer care and funding are not equal across Europe. There is a serious East-West divide with

respect to cancer mortality, spending on cancer, investment in prevention, and access to cancer drugs. Inequalities in cancer care are reflected in cancer patient outcomes, for example five-year survival in Romania is half that of France. Mortality could further decrease if more people had access to cancer care: if every country managed cancer as well as Sweden, an additional 270,000 people would live five years longer.

Tit Albrecht, Lead, IPAAC Joint Action, and an expert on National Cancer Control Plans (NCCPs), spoke about the importance of European Member States (MS) mapping the entire cancer trajectory and allocating adequate resources. The adoption of NCCPs will be vital in reducing the considerable inequalities across Europe by ensuring a more balanced and efficient use of resources for better prevention, outcomes, and quality of life for cancer patients and survivors. According to Albrecht, governments should take full responsibility for implementing NCCPs, which are a commitment toward people and not just a piece of paper. Albrecht noted that patient involvement in the implementation of NCCPs remained marginal.

The panel also included Silvia Franceschi, Scientific Director, Centro di Riferimento Oncologico, Organisation of European Cancer Institutes (OEI), who stressed the importance of improving cancer monitoring in Europe. Franceschi shared information about the European Network of Cancer Registries (ENCR/JRC), disclosing that only half of the EU population is covered by Cancer Registries. This leads to fragmentation in cancer data across Europe, making it difficult to implement an evidence-based European Cancer Plan. More patients covered by registries, more coordination, and more granular data were the proposed solutions.

Kathi Apostolidis, President, European Cancer Patients Coalition (ECPC), and Barbara Wilson, Founder, Working with Cancer, provided some patient perspectives. Both stressed that cancer is more than just a medical problem; it affects all areas of life, from work and financial security, to patients' emotional condition and sense of self-worth. Apostolidis spoke about the need for a European Cancer Plan to address the aforementioned disparities and inequalities in cancer care across Europe. ECPC advocates for a package of minimum cancer services to become mandatory at EU level. Wilson communicated the importance of reintegrating cancer

survivors into the workplace and the necessity of European and national Cancer Control Plans having return to work objectives.

Martin Seychell, Deputy Director-General, European Commission Directorate-General for Health and Food Safety, stated that cancer is high on the EU's political agenda due to its burden in Europe and because there is a strong belief that by addressing system failures in cancer, there will be a benefit beyond cancer patients. The EU views cancer as a medical, social and economic issue and aims to tackle the disease in a holistic manner. Every key stage of the disease should be strengthened: prevention - including stepping up efforts to tackle risk factors like tobacco or obesity, which respectively account for over 30% and 20% of cancer cases; diagnosis; treatment; life as a cancer survivor, and palliative care. Big data has the potential to improve cancer outcomes and health system sustainability. Seychell reminded the audience that Stella Kyriakides, the European Commissioner-designate for Health, has been tasked with driving forward Europe's "Beating Cancer Plan" to support MS in improving cancer prevention and care. There will be a close link with the Research Mission on Cancer as part of the Horizon Europe programme.



According to Seychell, the EC has a convener role and stands ready to help MS identify priorities in cancer control, support the transfer of best practices through a dedicated portal, and scale up implementation.

From the national perspective, Mate Car, Assistant Minister, Ministry of Health Croatia, spoke about the opportunity of a European Cancer Plan to push countries forward in implementing NCCPs. According to Car, the factors that delayed development of a cancer plan in Croatia included a combination of lack of financial resources and lack of political will. Mike Morrissey, Chief Executive Officer, European Cancer Organisation (ECCO), began by thanking the EC for their openness and expressing hope that the EU will not look to reinvent the wheel, but draw on the excellent work that has already been done in the field of cancer control policy. According to Morrissey, more needs to be done on implementation of policy recommendations, including targets as part of a dashboard, aiming to level up the standard of care across the EU. For example, we have guidelines for three cancers since 2003 but only eight MS have implemented them, therefore having a European Cancer Plan without strong commitment to implementation would not solve our problems.

Representing the pharmaceutical industry, Alexander Roediger, Chair, EFPIA Oncology Platform, MSD, stated that the private sector has a role in helping countries narrow the gap in cancer treatment through sustainable innovation. There is no valuable innovation without a patient who can access

and benefit from it, he stated, and a European Cancer Plan could help foster accessibility to innovative therapies. Several initiatives to accelerate access to new cancer treatments are already underway across Europe, for example in the UK, Germany and Belgium, providing case studies that other countries could learn from.

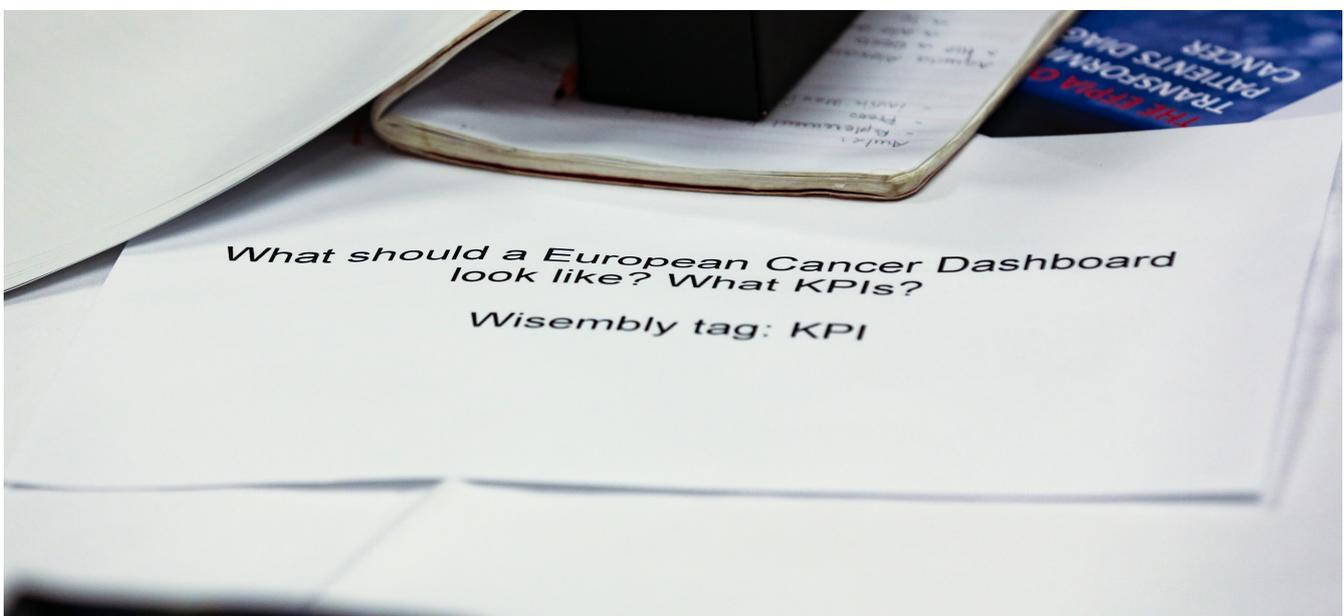
Although there are varying views on what a cancer plan should look like, it seems there is a consensus that, in order to be successful, such a plan must balance three objectives: to foster innovation, promote equal access, and enhance the sustainability of health systems. In order to move forward with drafting a European Cancer Plan a great deal of work remains to be done and, as Albrecht warned, we are unlikely to see a document in the immediate future, however, discussions during this session indicated growing momentum and strong support for the implementation of such a plan. The session concluded with a call to action urging the cancer community to continue with their hands-on efforts to improve cancer outcomes in Europe.

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Shortage of essential medicines An imminent health risk for patients?



Organised by the Directorate-General for Health and Food Safety (DG SANTE), European Commission

Over the past decade, the problem of medicine shortages has grown and is now affecting not only smaller Member States, but Europe in its entirety. Whenever prescribed medicines are not available in a timely manner, patients' health is put at risk. Simultaneously, the amount of time that healthcare professionals can spend with patients is reduced due to the increased necessity to invest more and more working hours into the management of shortages.

Given the urgency of the problem and the health risk that medicine shortages pose to patients, the Directorate-General for Health and Food Safety (DG SANTE) of the European Commission brought together different stakeholders to explore solutions.

Fixing the problem necessitates understanding its causes

The market for pharmaceuticals is complex, with 28 Member States applying different procurement procedures and tackling the problem of medicine shortages on their own, using diverse strategies. Causes for shortages vary,

but are mainly driven by manufacturing problems, linked, for example, to the increasing complexity of the supply chain, incidental quality issues and the dependency of the industry on active pharmaceutical ingredients which are sourced from outside the European Union (EU). In addition, the problem is influenced by supply management choices, commercial decisions, procurement processes and parallel trade, which is seen by countries as both a curse and a saviour.

To tackle these issues, both proactive and reactive solutions need to be found. However, Member States cannot achieve this alone, since medicine shortages are becoming a pan-European problem. To develop targeted solutions for both the national and the European level, an inquiry led by the EU institutions into the factors causing medicine shortages is needed. Such an analysis should be taken as a first step towards finding solutions that will help to solve preventable shortages. This is also one of the demands of the European Association of Hospital Pharmacists (EAHP).



Collaboration – the key to success?

Responsibility to ensure that medicinal products are available falls to all stakeholders, and isolated strategies will likely not be successful. Consequently, Brigitte Zarfl, Minister of Labour, Social Affairs, Health and Consumer Protection, Austria, and Kristin Raudsepp, Director General, State Agency of Medicines, Estonia, and Co-chair, EMA-HMA Task Force on Availability of Authorised Medicines, agreed on the need to deepen collaboration with other Member States and between stakeholder groups. Both countries are already working towards increased stakeholder engagement, for example through the creation of a dedicated task force or through taking preventive measures collaboratively. These initiatives are following the example of the Task Force on the Availability of Authorised Medicines run jointly by the Heads of Medicines Agencies (HMA) and the European Medicines Agency (EMA).

Touching on the mission letter of the Commissioner-designate for Health, Stella Kyriakides, the role of the EU as innovator and leader was underlined. Efforts should be made to strengthen and expand this role. In the field of medicine shortages this would mean having the EU act as a facilitator among the different Member States, coordinating their individual competencies and solutions. Cooperation with all actors is the way forward, and patient organisations must be at the forefront. Patient representatives present in the audience emphasised the distress patients experience in the face of uncertain medical supplies. For many, the reasons essential medicines have been disappearing from the market are irrelevant - patients simply want their medicines to be there.

Novel technology as a possible solution

Emerging technologies and models were discussed as potential answers to the medicine shortage problem. The European Medicines Verification System was implemented in accordance with the Falsified Medicines Directive to prevent falsified medicines from entering the legal supply chain. It was not designed to address medicines shortages, and the difficulties to use the information contained in the system were noted. Other solutions, such as the assessment of emerging shortages via blockchain technology, could be a future option.

Can the medicine shortage problem be solved?

Given the complexity of the pharmaceutical supply chain, solutions need to consider national particularities. However, despite these challenges, the panellists agreed that they can be found provided that transparency, collaboration among stakeholders and changes to policymaking are achieved. Setting up compulsory stocks for essential medicines, exploring the possibility to increase prices for essential medicines, forming task forces comprised of supply chain representatives and applying best practices from other areas such as the stakeholder model used for the European Medicines Verification System were some of the ideas put forward at the end of the discussion. The months ahead will show which of these suggestions can be turned into solutions to alleviate the problem of medicine shortages for all European countries.

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Public stewardship & economic globalisation A participant-led conversation



Organised by Main Association of Austrian Social Security Institutions

Josef Probst, Director General, Main Association of Austrian Social Security Institutions, welcomed participants to this “Open Space” format session, where all participants had the opportunity to set the agenda and identify disruptive, actionable and sustainable solutions. Nick Fahy, Senior Researcher, Primary Health Sciences, University of Oxford, moderated the session and Rachel Melsom, Director UK and Europe, Tobacco Free Portfolios, provided insights into her challenging but fruitful work with the finance sector. Beautiful drawings by Becky Hatchett and Naomi Fein from Think Visual illustrated the discussion.

The ascent of globalisation

Globalisation is everywhere and everything, the clothes we wear, the food we eat, the transport we use. Nowadays, it is normal for a product to pass country borders many times before it is sold or distributed, for example with pharmaceutical products. But globalisation also brings a disruptive change in power relations between globally operating companies and public actors and in recent decades, globalisation has led to the fundamental transformation of our economic system. There is now a tension between the positive aspects of globalisation and the challenges that come with it.

What are the tensions between global issues and local public actors?

Existing economic frameworks and free trade agreements largely protect the interests of international private companies. Moreover, these frameworks and agreements might not

always be up to date, because globalisation is progressing at speed and globally acting companies are growing in size and power. As a result, public services are becoming increasingly vulnerable to liberalisation efforts. But, what does that mean for public health and what are the tensions between globally acting companies and local governments? What does globalisation mean for public goods, for instance, the healthcare system we created in an era before this rapid globalisation? The sector has been confronted with monopolistic pricing strategies, increasing demand and the challenge to maintain solidarity-based healthcare services.

“We don’t do ethics and morals, we just do numbers.”

This shocking quote was from a person working in the finance sector when he was asked to participate in a session on tobacco divestment. When faced with this mentality, one could easily walk away, but that was impossible for Rachel Melsom. She highlighted that the healthcare sector needs to explain the issue in the language global and financial actors use: the challenge is to translate morals and ethics into numbers. Her organisation does this to convince financial institutions to divest from tobacco. And the financing of the tobacco industry is a good example of a global issue.

Melsom emphasised how a low-key, behind the scenes approach was crucial to the success of Tobacco Free Portfolios’ work. Tobacco Free Portfolios are not threatening to the finance actors they meet with (as non-investors they are not competitors), they can rather add to their knowledge base



and quietly facilitate evidence-based divestment decisions. This allows the finance actors to take on the powerful role of being “the leaders that helped find the solution.” Melsom described how this iterative process, involving multiple stakeholders from lawyers, to health actors, to policymakers and civil society, helps to facilitate their work and create an environment which makes these divestment decisions possible.

45-minutes to save the world

Under the overall session theme, participants defined topics they wished to discuss and then distributed themselves around the room according to the six chosen topics. The topic convenors each introduced their topic to the small group through videos or case studies. After a 45-minute discussion, each group reported back on their chosen topic. To provide a framework, for each topic participants were asked to consider who the stakeholders were; what kept the stakeholders polarised; what pulled stakeholders together; what could resolve the tensions between them, and could any next steps be identified?

Trade agreements versus public health regulations

Unlimited corporate power and for-profit short termism driving corporate behaviour versus health, well-being and social rights and protections was discussed. Trade lawyers are almost exclusively sat within corporate organisations and there is a lack of understanding of the externalities of globalisation, a lack of transparency and corruption. The public would benefit from a greater understanding of the real global and financial impact of unrestrained trade liberalisation without social protections – for example through the provision of transparent data on the costs and consequences. The SDGs could help provide a framework for this debate. Regarding short term actions, NGOs need to monitor the workings of trade deals and make their findings public with the aim of increasing transparency, and where they are the appropriate fora for precipitating action, they should be afforded more resources. Participants thought that it was vital to ensure that the public can access the data, engage with the issues and understand the debates, as this could really change thinking in this area.

Trade agreements versus access to affordable medicines

There is a tension between trade agreements and access to medicines, where for example individual nation states

such as the US or bigger entities such as the EU with strong pharmaceutical industries act as the custodians of these private interests. Participants thought that forces pulling these areas together (i.e. innovation as a common goal, accessibility of medicines, improving public health) could be more integrated into trade agreements and mechanisms for innovation. Nick Fahy commented that this example shows that even states are not this locus of public balancing of goals – do we need another kind of forum where such discussions might take place? One answer could be TRIPS or WTO - but how balanced are they? The discussion showed that we need not only to discuss protection regulations but more broadly interests on a global level. Trade is another example of an area where the health community need to be engaging more widely – this time talking to trade lawyers and bringing issues to the table in a language they can understand.

Free movement of goods versus national supply needs

Shortages occur in part from tensions between the free movement of goods on the one side and national supply needs on the other. The main group of interests profiting from free movement of goods are parallel traders. Forces worsening these tensions are the commercial interests of parallel traders, diversified pricing and reimbursement systems between different Member States (MS), and connected to this the ability of different MS to pay for pharmaceuticals and other products. There was consensus that shortages and availability issues should be addressed, and recognition that an informal alliance between patients, the pharmaceutical industry, and payers already exists. However, we need more transparency about why and at what level shortages happen, and to clarify the obligations of actors. Moving forward, MS need to ensure this issue is addressed at an EU level (not necessarily by EU institutions – it could be an alliance of MS), as national solutions are inappropriate. We need to stop pointing fingers and engage in disruptive action to align the interests of the different stakeholders.

Public versus private health service provision

To what extent is there a tension between profit and public interest? Forces pulling these two areas apart were identified to be greed; the element of choice (especially in its capacity in allowing for risk selection and avoiding risk pooling), and inequalities. Conversely regulation and regulatory processes; the diversity of products and services, and the desire to live in

a clean and healthy environment brought interests together. Key takeaways for the group were that the health sector has an immense impact on the economy, and that public health is an economic efficiency and a precondition for growth and development. In terms of next steps, the group thought that governments and public sector stakeholders must act to prevent market failures. It might be worth further investigating how the benefits of governance or business models in the private sector could be mimicked by public providers to ultimately deliver the same quality of care.

Global innovation meets local healthcare

There is a tension created by national healthcare systems faced with globally driven innovation trends. Forces enhancing these tensions were identified as the financial interests of profitmaking companies; the interests of local budget holders; self-interest, and the fear of losing status or freedom that comes with low transparency. A faster pace of change and the increased degree of complex developments, that challenge public sector decision-making and the building of associated bureaucratic structures to address this, takes time and compounds issues. Forces that pull together were the potential for increasing efficiency and the patient interests that many stakeholders have very strongly in their missions. Participants thought the gap could be closed through piloting innovation with mandatory uptake, as well as faster legislative updates. Some takeaways considered were that there could be lessons learned from other sectors like the music industry, but overall there needs to be more interaction between the different interests for better mutual understanding of the needs of a citizen-driven healthcare system.

The global problem of corruption in health and healthcare

This is not just a problem for the global south, it is also an EU problem and the more dysfunctional the system, the harder it is to tackle the problem. The tension is often between morals and ethics, power and greed. Corruption happens behind the scenes at many levels - it can be found at a micro level (patient and doctor), meso level (institutional) or macro level (policy). To better address this problem, corruption needs to become more visible so there is greater public and patient awareness of it. New ways to tackle it were discussed, including better implementation of regulations and guidelines, patient awareness campaigns, and publicly available registers, for example on hospital-level corruption indices.

Climate change and the health sector

Group discussions on this topic largely reflected the information deficit that exists about the contribution of the healthcare sector to greenhouse gas emissions. There are opportunities to reduce waste through greater patient knowledge and awareness of the carbon footprint of different treatment options, for example there may be more technologically oriented greener solutions available than travelling to healthcare providers. Of course, in this area prevention measures - keeping people healthy in the first place and avoiding treatment and the use of medical facilities - is the best solution. However, there are opportunities to reduce waste and there should be greater awareness amongst health professionals themselves about how the sector can contribute towards change. An outstanding question was which party should and could contribute to disseminating this knowledge and raising greater awareness?

Do complex systems need complex solutions?

Clearly, we are in a phase where the interests we are passionate about reach beyond current structures and processes for dealing with them. The time-dimension and the tension between certainty and agility - the "agility gap" is key; we rely on processes of regulation which are oriented towards certainty and fear and take time to develop, but we need agility and swift change within health systems which these processes don't comfortably meet. Discussions concluded that the complexity of globalisation requires shared stewardship and a shared long-term vision amongst public and private actors. And this in turn requires the use of accessible language and transparency to increase communication. Do we stop at simple solutions too readily? Every group discussion highlighted the complexity of our systems composed of different actors with different interests pulling us in different directions. Finding a way to successfully navigate these complex systems through building bridges between different sectors, including learning common languages and changing perceptions about what is normal and accepted, will be challenging. However, the example of Tobacco Free Portfolios revealed what is possible. Nick Fahy and Josef Probst both highlighted that outcomes will be collated and the conversations on this topic will continue.

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Save blood, save lives Improving patient outcomes through Patient Blood Management

Organised by Vifor Pharma



Is there a better way than blood transfusions to deal with patients who are anaemic and need blood – a better way for patients, and a better way for the health system?

This workshop discussed evidence in this area and explored ways to improve clinical practice and policies through Patient Blood Management (PBM). The event was moderated by Anna Mezzacasa, Medical Lead Iron Franchise, Vifor Pharma.

The value of blood

Blood is a precious resource. Blood components are used to save and improve the lives of millions in Europe each year, for instance, during hospitalisation, surgery and in the treatment of chronic disease resulting in iron deficiency and anaemia. In these cases, red blood cells which contain haemoglobin, are transfused to increase iron levels. According to the World Health Organisation, access to safe, quality blood is indispensable in order to provide comprehensive healthcare for all. Keynote speaker Axel Hofmann, Assistant Professor, University Hospital Zurich and Trustee, International

Foundation for Patient Blood Management, distinguished blood as a key infrastructure, as important as water or energy.

While blood demand is on the rise due to ageing populations, the donor population is decreasing. With the gap between the two populations increasing annually, blood is becoming harder to source. At the same time, according to Hofmann, most blood transfusions are given outside recommended transfusion guidelines. In fact some data from an International Consensus Conference on Transfusion Outcomes in 2011 suggested that almost 60% of transfusions given in clinical practice were inappropriate, while consensus could not be reached regarding almost 30% more. This is startling given the unnecessary provision of blood to patients before medical procedures creates a needless burden on patients and a cost to the healthcare system. With this introduction, the panel of speakers investigated how PBM could minimise or eliminate the causes of anaemia and blood loss without resorting to unnecessary transfusions.

What is patient blood management?

PBM is a multidisciplinary approach intended to optimise the care of patients by managing and preserving their blood. In practice it involves three main elements:

1. Optimisation of the volume of red blood cells through management of anaemia before and after surgery;
2. Minimisation of blood loss through inpatient and intraoperative measures; and
3. Harnessing and optimising the tolerance of anaemia by strict indication concerning blood transfusion.

Evidence suggests that PBM results in the improvement of patient outcomes, including a decrease in-hospital mortality, reduced length of hospital stay, lower rates of infection, decreased risk of acute myocardial infarction/stroke and reduced rates of hospital readmission. With anaemia and iron deficiency found in 40% of patients hospitalised in the European Union (EU), PBM has the potential to not only improve outcomes for patients but to also create efficiency gains for hospital budgets. Danny Havenith, CEO, MercurHosp (a Belgian Hospital) and Board Member of the Belgian Association of Hospital Directors, stated that PBM brings real added value at a time when hospitals are looking for new, innovative cost reducing models.

Lack of awareness and barriers to patient blood management

Despite its clear advantage, PBM implementation remains limited in hospitals and in national health systems. Why is that? Elvira Bisbe Vives, Doctor of Anaesthesiology, University Hospital Mar-Esperanca, Hospital del Mar Medical Research Institute, believes the benefits of PBM remain largely unknown among both patients and healthcare professionals. The roll-out of PBM practice requires an organisational and cultural shift, involving healthcare professionals, hospital managers

and regulators. One of the main challenges preventing this is the fact that transfusion is a complementary treatment and there is no doctor specialised in this practice, as it is usually requested by surgeons.

Patient blood management legislation and best practices

When talking about blood policies, it seems clear that policymakers' focus is on blood supply rather than management and prevention. But PBM is not new and dates back to 2010, when the World Health Assembly endorsed it, and 2016, when the European Commission adopted two practical implementation guides for PBM directed to hospitals and national authorities. However, "only Italy and Portugal have PBM legislation in place in Europe," highlighted Christoph Zenger, President of the International Foundation for Patient Blood Management. According to speakers, there is a lot that EU countries could learn from other countries both inside and outside the EU, latter examples include countries such as Australia and the United States of America.

From supply management to demand management

Clearly, cultural and organisational barriers are slowing down the adoption of PBM in Europe and both awareness raising and political commitment are needed to drive change in this area. As stakeholders demand an acceleration of this process by adopting legislation on PBM, the reopening of the EU Blood Directive offers an opportunity to have PBM's value recognised. In parallel, there is a need to raise awareness amongst healthcare professionals, and medical students, to support a cultural shift, and to inform patients about the alternative to transfusions. Ultimately, PBM allows a move away from supply management (blood supply) to demand management – as stated by Axel Hofmann, "this is a trend we are seeing in many other sectors such as energy and water, so why not for blood?"



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Towards the Economy of Wellbeing People, money and EU policies in the 2020s



Organised by the Finnish Ministry of Social Affairs and Health in collaboration with the European Observatory on Health Systems and Policies

Well-being is a value in itself, but the Economy of Wellbeing recognises the virtuous cycle of sustainable economies and well-being. Measuring well-being requires looking beyond GDP. This session organised by the Finnish Ministry of Social Affairs and Health together with the European Observatory of Health Systems and Policy focused on charting the way forward towards the Economy of Wellbeing. How can the approach contribute to the well-being and resilience of society and economic growth, and what could and should it mean for EU policy and practice?

During its previous Presidency of the Council of the European Union in 2006, Finland promoted the Health in All Policies (HiAP) approach, which underlines the importance of intersectoral policy development to achieve health outcomes. Thirteen years later, Finland is introducing the Economy of Wellbeing into EU policymaking. The Economy of Wellbeing spans beyond HiAP: Through the lens of economic, employment, education, social and health policies in the EU, it looks at how wellbeing and economic outcomes are interdependent and mutually enforcing. Economic growth affects people's well-being, and vice versa.

“The Economy of Wellbeing is a reminder to us all that promoting people's well-being is a central objective of the EU”, noted Eila Mäkipää, State Secretary at the Ministry of

Social Affairs and Health of Finland in her opening address. It builds on the European Pillar of Social Rights and contributes to the implementation of the UN Agenda 2030. Mäkipää highlighted that whilst the role of the well-being sector for competitiveness is clear, there is a need to better understand how well-being policies can boost productivity, generate growth, create jobs and contribute to economic and social stability and sustainability. Importantly, the Economy of Wellbeing places individuals in need of protection at the core of policy measures.

The co-moderators Päivi Sillanaukee, Director-General of the Ministry of Social Affairs and Health, and **Josep Figueras**, Director of the European Observatory on Health Systems and Policies, called for innovative and interactive discussion and disruptive ideas from the audience. What does the Economy of Wellbeing mean in theory and how does it translate into practice - and what role should it play in the EU decision-making processes, including with a view to the programme of the new Commission?

Esko Aho, CEO of Verbatum and former Prime Minister of Finland drew in his keynote speech from examples from history on how increase in productivity has fueled economic growth and the well-being of people. Aho reminded participants that the economy and well-being go hand in hand, pointing out

that it is hard to find a successful, happy country having one but lacking the other. Aho highlighted demographic change as an example of a transformative phenomenon that requires a Whole of Society approach. Societies across the globe face the phenomenon of ageing – without being prepared for it. Longevity entails longer careers, tax revenues and business opportunities. Aho raised four main points. First, addressing demographic change must be based on shared value – in short “saving the world has to become good business”. Second, the Silver Economy is here, and companies need strategies for it. Third, there is a need for a change of mindset when it comes to the older generation. Age does not equal less productivity; what one lacks in mobility and efficiency, one can compensate with experience. Finally, digitalisation enables moving from standardised solutions for all towards more personalised solutions, enabling – and forcing – decision-makers to rethink policies.



The intersections of the economy and well-being in theory and practice

The first panel discussed the Economy of Wellbeing as a theory as well as avenues towards practice, informed by input from session participants. To kick off the panel, the audience singled out three focal points as the most important to put the Economy of Wellbeing at the centre of policy making: intersectoral cooperation, evidence on the impact on economic productivity, and measurement and indicators for wellbeing.

Jonathan Cylus, Senior Research Fellow and London Hub Coordinator at the European Observatory underlined the need for a more equitable approach towards older people in working life. For example, economic aspects are needed for retirement policy, but trying to make one size fit all might have harmful effects on well-being. On the other hand, the scale of informal care is invisible but considerable in many European countries. Cylus described the Economy of Wellbeing as more personalised and flexible policy making. Data is the raw

material for all of this, noted Antti Kivelä, Director for Capacity for Renewal at the Finnish Innovation Fund Sitra. Sitra has developed a system (IHAN) for the exchange of well-being data. The EU and national governments play a central role in developing rules for a well-functioning, safe and fair data economy.

Sarah Thompson, Senior Health Financing Specialist, WHO Barcelona Office for Health Systems Strengthening, highlighted the importance of looking behind the figures. Unwell health systems can undermine people’s well-being. Gaps in health coverage make people use out of pocket payments that push them into poverty and into making difficult choices between health, food, and housing, among others. For improved measurement of well-being, Thompson suggested stories and lived experiences – matched with the associated policies – metrics on inequality, and better recognition of the potential challenges in the current measurements. **Liisa-Maria Voipio-Pulkki**, Director General at the Finnish Ministry of Social Affairs and Health, reminded us that the health and social services sector in itself is a major contributor to the economy, with additional possibilities for growth with digitalisation.

The latter part of the session shifted the focus from Economy of Wellbeing as a concept into its practical utilisation and implications in EU policy. Pasi Mustonen, Counsellor for Health at the Permanent Representation of Finland to the EU, presented the process of drafting the Council conclusions on the Economy of Wellbeing. The aim is to foster continuity for the approach, and to take forward a genuine change of mindset. This requires highlighting the political message of the link between economic growth and well-being and proposing practical measures. Health is a key component of the conclusions, Mustonen noted, including health promotion and prevention, mental health, and digital health. He added that impact assessments must play a central role for evidence-based policymaking, and the role of the European Commission is important.

The discussion with comments from the audience circled around opportunities and barriers for integrating the Economy of Well-being into the processes and instruments such as the European Semester and impact assessments. The European Pillar of Social Rights was highlighted as an important basis, but participants noted that the Economy of Wellbeing goes beyond the Pillar.

Croatia's Assistant Minister for Health Mate Car stressed that healthy ageing will be high on Croatia's agenda during the upcoming EU Council Presidency. This requires thinking of structures that can support horizontal work and help see health as an enabler. Ortwin Schulte, Head of Unit Health Policy, Permanent Representation of the Federal Republic of Germany to the EU, noted that the different trios will provide opportunities for complementarity in themes that touch upon different aspects on wellbeing.

Martin Seychell, Deputy Director-General, European Commission, Directorate-General for Health and Food Safety drew attention to the multiple information sources about well-being: when reporting about perceived health, people often intrinsically think of factors of well-being as well. Seychell pointed to the need to look beyond the average when measuring progress on SDG 3 – ensuring healthy lives and well-being for all at all ages – and using it to inform policy. Accessibility, effectiveness and resilience continue to be the Commission's key pillars for assessing health, but there might be a need for a shift of angle. Europe is doing well in the average picture, but the key concern are the rising inequalities in and between Member States. Seychell highlighted the Commissioner Designate Kyriakides' focus on prevention and drew attention to mental health, which is linked with a number of aspects of well-being, and is estimated to have a 4 % annual impact on GDP in the EU.

Tuija Brax, General Secretary, Finnish Heart Association and Board Member, European Heart Network (former Minister of Justice of Finland) highlighted the return of investment in prevention. Brax called for a benchmarking system, "a Pisa of health and well-being", and flagged that taxation is also an area where a more active approach could be considered by the Commission. Brax underlined the legal basis for right to health enshrined in the legally binding Charter of Fundamental Rights of the EU.

As an example of an intersectoral policy and budgetary planning, Sillanaukee highlighted the new Finnish Government's plan with seven strategic pillars that all have prevention and health promotion integrated in them.

Moving forward, leaving no-one behind

The inclusivity of the Economy of Wellbeing was discussed quite a few times during the session. Assessing the impacts

of policy measures on wellbeing and using metrics that are sensitive to inequalities is essential for ensuring that no one is left behind. The Economy of Wellbeing provides a lens to think of economy and allocate resources, as the effects of boosting the well-being of people will be felt in other sectors. At the same time, the synergy should not be taken for granted, but requires and will benefit from continuous discussion.

Council conclusions as such might not be disruptive, but they may help bring health to the tables where health policy is usually only discussed in a side sentence. Questions such as what would well-being impact assessments look like in the EU context, who would be held accountable, and what should the Economy of Wellbeing mean vis-à-vis the European Semester – traditionally focused on economic and fiscal policy but with evident links to many other areas – remain open for future discussions.

It became clear that the EU needs – and could be ready for – a horizontal approach on the well-being of its citizens. With a long-term strategic approach and taking on board all sectors and stakeholders, the Economy of Wellbeing can evolve from a healthy dose of disruption into a transformative change of paradigm for a more sustainable future for societies.



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Medical use of cannabis and cannabinoids Is the grass always greener?

Organised by Trigal Pharma and CannPico



The introduction of cannabis and cannabinoid products into modern medicine has led to controversial debates involving health professionals, patient organisations, pharmaceutical companies and the private sector, as well as the general public. This lunch workshop – organised by Trigal Pharma and CannPico and moderated by Natasha Azzopardi-Muscat, President of the European Public Health Association (EUPHA) – aimed at discussing the potential risks and benefits, and regulatory challenges in a diverse European legislative landscape. In accordance with the conference theme, the session was based on the underlying question as to whether or not the use of cannabis products would disrupt conventional treatment options - and what the implications of such disruption might be.

Due to the complexity and vast variety of substances involved, **incorrect use of terminology** leads to frequent misunderstandings and misinterpretations. In the general discourse, terms are often used synonymously, not differentiating between recreational and medicinal use of cannabis, confusing various types of cannabinoids, and not distinguishing between different components such as

Cannabidiol (CBD) and Tetrahydrocannabinol (THC). The inconsistent use of terminology, however, makes it difficult to communicate potential health-related gains and risks. Investing in awareness raising and education about the various substances and usages was strongly emphasised as important by the panelists as well as the audience attending the session.

Limited evidence on the medicinal use of cannabis and cannabinoid products was further discussed in the workshop. Cannabis is a psychoactive plant containing more than 500 components. Certain cannabinoids and their synthetic derivatives do have therapeutic properties for a variety of indications, but not all of the cannabinoid components have been identified and researched yet. Two of these, however, have been subject of scientific investigation into their pharmacological properties: THC and CBD ([Lafaye, Karila, Blecha, Benyamina, 2017](#)). Philip McGuire, Head of Department of Psychosis Studies at King's College London shared findings of his research on the effect of THC and CBD molecules. He explained that while THC seems to produce anxiety and paranoia among healthy people, CBD may have an anxiety



reducing effect. The molecules hence show opposite effects on human brain function ([McGuire et al., 2018](#)).

Both Paola Kruger, EUPATI Fellow from Italy, and Liesbeth Vandam, Head of Sector 'Support to Policy', representing the European Monitoring Centre for Drugs and Drug Addiction, confirmed the potential health benefits in several therapeutic areas and the use of CBD to treat e.g. seizures in childhood epilepsy. It must be noted, however, that cannabinoids may relieve symptoms of some illnesses, yet the causes are not addressed. While the panelists agreed that further research is needed, Paola Kruger, EUPATI Fellow from Italy, strongly emphasised the importance of incorporating the patients' voice in research and decision-making.

Lacking awareness and insufficient scientific evidence are also challenging decision makers to develop adequate **guidelines and regulations**. Vandam highlighted in this context the existing patchwork of regulatory frameworks, also regarding

insurance coverage. Lacking consensus and insufficient transparency in terms of responsibilities further complicate the decision-making process, creating loopholes and hence unintended opportunities for investors. Potential harmful implications regarding the marketing of cannabis products to young people for example – strengthening the recreational market without considering the potential negative effects of cannabis use – need to be considered.

The controversial nature of the topic mirrored in a lively discussion with the audience, which concluded with a **set of steps** that should be taken to address the various challenges related to the medical use of cannabis and cannabinoids. It was emphasised that more research is needed on the use of these products to have clear evidence about the actual harm and benefits. Furthermore, clarity about the terminology used is considered essential to make informed decisions, which applies not only to patients but also to health professionals and the general public. What is needed to achieve this level of awareness is more education on the various types of products and the potential implications of their use. Avoiding downplaying the negative effects of recreational use of cannabis remains crucial in this context. Finally, a regulatory framework needs to be established providing guidance for all stakeholders involved.

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Obesity in Europe – time for a new approach? Exploring the paradigm shift towards obesity as an NCD

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Organised by the European Association for the Study of Obesity (EASO)



From the start, Jacqueline Bowman-Busato, Policy Lead at EASO, challenged the session participants by asking a rather controversial question: What would happen if Europe approached obesity like other major chronic diseases and focused on addressing the biological causes in approaches to policy along the obesity continuum?

The case for a paradigm shift

Obesity has genetic and biological components, but have these led to the current epidemic? To date, most research on obesity has focused on individual behaviour change interventions. Unfortunately, we still see limited to no effects especially when looking at follow up studies in which initial outcomes do not seem to be sustainable in non-research settings. In making the case for reframing obesity as a chronic, relapsing disease, Abd Tehrani, NIHR Clinician Scientist from the University of Birmingham, UK presented data on the genetic components of obesity risk and explained how achieving, and most importantly sustaining weight loss on an individual level has been unsuccessful.

The prevailing paradigm, which characterises obesity as an individual choice, is therefore incorrect the implications of an individual approach also contribute to the stigma of people living with obesity. Indeed, Michele Cecchini, Senior Health Economist at the Organisation for Economic Co-operation

and Development, pointed to the fact that girls living with overweight are 3 times more likely to be bullied in school. In addition to the individual burden associated with the disease, Michelle Cecchini also highlighted the societal cost and impact of obesity: data shows that in particularly boys living with obesity are less likely to report finishing secondary education as compared to their peers. This will affect the workforce of a country and consequently has a cost associated with it from a governmental perspective, making also a fiscal case for improved approaches.

Given the broad environmental factors that lead to an increase in the prevalence of obesity on top of a large variety of medical conditions and genetic predispositions, it is imperative that we address biological and environmental drivers across the life course and take a 'whole systems' public health approach to prevention and treatment. Tehrani also called for more focus on identifying the particular drivers of weight gain in patients rather than just on weight loss, comparing it to approaches to other conditions: 'If you had a patient suffering from anaemia, you would not just try to treat the anaemia – you would try to find and treat the underlying cause.'

Dissenting voices

In a highly interactive session including a 'fishbowl' style discussion and mind-mapping activities, the session

participants considered what this shift might mean for public health policy and practice in the coming decade.

Concerns were raised that constructing obesity as an illness would not help to de-individualise the discourse and would divert attention from the structural and environmental causes of ill health. While people have not changed in previous decades, the food environment has. If we want to stop obesity rates from rising, our focus has to be on this broader environmental policy change, some participants argued. Mechanisms, such as INFORMAS, exist to monitor food system policies and should be better utilised to this end.

Discussants came together around the notion that if we want to successfully change the current obesity narrative, we need to address multiple underlying challenges with an integrated approach: the awareness of biological drivers of obesity as a non-communicable disease, while not discounting the interplay of environmental determinants, the discrimination and stigma that is often associated with obesity, current infrastructures and health systems, and data on health outcomes. Given the breadth of these challenges, it is urgent that we look upstream and adopt a systems-wide approach to tackle obesity and address its drivers, shifting away from our current focus on individuals.

Multifaceted and multi-sectoral action is necessary. Better provision is required to support those already living with obesity. Even basic supplies such as appropriately sized CT scanners are lacking in many countries. At the same time, prevention policy approaches need to involve a wide range of stakeholders working together. If we wish to address the obesity challenge in a holistic way, we need to ensure that not only governments but also civil society organisations, patients themselves as well as the private sector, including the food sector, are consulted. Anne-Sophie Joly, a Patient Advocate from the European Coalition for People Living with Obesity, emphasised the need to empower people in making choices and to be free to do that with the right information.

Policy for the next decade

The workshop was about action as well as discussion. In small groups we were tasked with imagining an ideal future and developing policy proposals that might take us there. A series of specific policy proposals and some broader policy orientations were developed focusing on four areas:

awareness, stigma, infrastructures and health systems, and data.

Awareness:

- Government should tax the food industry and ensure that the money is reinvested in health promotion activities.
- There should be an awareness campaign with the message that obesity is a chronic illness

Stigma:

- Prevention of discrimination through legislation (e.g., in the workplace).
- Integration of obesity and nutrition education in medical school.
- Shift the blame from individuals to wider societal issues by addressing poverty, food environment & marketing, working conditions, preferably through a whole of Europe approach.

Infrastructure:

- Healthy urban planning – develop health promoting benchmarks that must be adhered to in urban planning projects.
- Develop policies that focus on the upstream determinants of health inequalities (e.g., income and housing).
- Consider legal changes to make regulation for public health easier.
- Rethink stakeholder engagement where there are potential industry conflicts of interest

Data:

- Collect data on biological and environmental drivers - for example, there should be benchmarking of the consumer basket, with the food industry held accountable if their basket does not measure up.
- Disrupt the financial system by producing credit cards that only permit the purchase of healthy foods.

What next?

However compelling our case, whether labelling obesity as a chronic disease will become the new paradigm remains to be seen. The policy priorities developed at the EHFG will be crafted into a call for action, so watch this space! In the meantime, EASO will continue to promote the whole systems approach at the policy and practice level in Europe.



We are what we eat The power of a healthy gut and disruptive nutrition policies



Organised by United European Gastroenterology (UEG)

Obesity and related chronic digestive diseases have become a Europe-wide epidemic, with the World Health Organization (WHO) indicating that one in three of us is now considered obese or overweight. In recent decades, food supply and eating habits have moved from basic and wholesome towards ultra-processed foods with high levels of salt, sugar, and fats, leading to an increased prevalence of obesity and its associated morbidity and mortality. We must act now if we are to tackle the rising incidence of diet-related diseases and their associated healthcare burden and economic cost. Debate around existing and future nutrition policies aimed at altering eating habits is urgently needed, and that is exactly what this interactive session, moderated by Anya Sitaram, Rockhopper Media, aimed to deliver.

Diets, drugs and the microbiome

Opening the session, Markus Peck-Radosavljevic, Chair, Public Affairs Committee, United European Gastroenterology (UEG), emphasised the power of a healthy gut. The human gut harbours approximately 100 trillion diverse microbes called the microbiota, which play a fundamental role in overall health and well-being. High bacterial diversity is generally seen as a positive indicator of a healthy gut, with lower diversity often observed in those suffering

from a variety of diseases including chronic digestive diseases, cardiovascular diseases, and Alzheimer's disease.

Environmental factors related to diet, particularly processed foods and medicine use, are primary determinants of microbiota composition. As Peck-Radosavljevic highlighted, the increasing consumption of ultra-processed foods is therefore of deep concern. These fast foods often go through multiple processes and modifications prior to consumption and typically contain many added ingredients and chemicals. The use of medicine was discussed as another primary factor affecting gut microbiota composition. Common drugs used to treat infections have been found to decrease microbiome diversity, proving the foods and medicines consumed determine microbiome diversity and thereby our health.

Solutions presented

Stefan Ullrich, CEO, Biosys UK Limited, presented an alternative for the use of antibiotics in the treatment of clostridium difficile infections (CDI). Despite the complex nature of this topic, the conclusions were clear: orally administered polyclonal antibodies can be used as an alternative to antibiotics in the treatment of

CDIs. These polyclonal antibodies have the ability to target specific pathogens without negative effects on the natural microbiome.

Ronit Endevelt, Director of the Nutrition Division, Public Health Services, Ministry of Health, Israel and Nikolai Pushkarev, Policy Coordinator Food, Drinks & Agriculture, European Public Health Alliance (EPHA), both argued for the need to break through the inertia surrounding nutrition policies. In order to counteract the challenges posed by obesity in Israel, Endevelt explained how the Israeli Ministry of Health had created a nationwide project to promote the benefits of a prudent diet as well as establishing a Regulatory Committee to propose and enact nutrition policy legislation, in order to achieve an improved food environment. The Committee met with experts, conducted focus groups, and invited civil society to express their views on steps the Ministry should take. Nine key areas of action were identified, and legislative steps initiated. The process was not without obstacles, with opposition from the side of the food industry and collaboration required between various ministries. Though, as Endevelt reiterated, healthy eating is now viewed in Israel as a basic human right, rather than a punishment.

Acknowledging Europe's need for a similar approach, Pushkarev reiterated that the current isolated initiatives implemented to tackle nutrition-related issues, whilst worthwhile, are not enough. In order to stimulate widespread change, we need to collectively strive for intersectoral action. The steps needed to tackle the crisis are not a mystery, Pushkarev stated, referring to the evidence-based WHO best buys ([World Health Organization, 2017](#)) which provide policymakers with recommended interventions to address noncommunicable diseases (NCDs). He stressed that diet-related health issues need to be seen as collective rather than individual issues, and with the advent of various digital developments, such as Artificial Intelligence (AI) and mHealth, we should not forget about the upstream causes of disease, which ultimately lie in our environment and are in need of immediate disruptive change.

But what about the joy of eating?

Taste, during an interactive discussion, was determined to be one of the biggest personal challenges to healthy eating. Both Peck-Radosavljevic and Endevelt agreed with this sentiment, indicating that the addictive properties added to ultra-processed foods, along with their convenience, present a crucial problem. A change in the food environment is fundamental in shaping people's choices: by making the choice of healthier foods the most accessible and affordable option, they will become the natural choice for consumers. The panellists unanimously agreed on the need for the introduction of a comprehensive range of policies to shape the food environment, including taxation of unhealthy foods, implementation of food marketing regulations, and (echoing the Israeli example) public health and media awareness campaigns on what constitutes a healthy diet.

Moving forward

The conclusions from this workshop were clear: given the diet-related health crisis facing many countries in Europe there is urgent need for a change in behaviour and attitude towards food consumption and production. As Endevelt alluded, change cannot be implemented overnight and initiatives carried out in isolation are unlikely to achieve a shift towards healthier diets. In order to make lasting changes with widespread impact, it is essential to employ a multi-stakeholder approach which aims to create environments for individuals and communities that are conducive to limiting the consumption and production of unhealthy foods. As was emphasised throughout the session, eating healthily should be viewed as a basic right and not a punishment - food for thought indeed.

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Making real-world data real New methods for EU health technology assessments

Organised by Vital Transformation, supported by Zorginstituut Nederland



Zorginstituut Nederland

With the increasing pressure on governments to control budgets and a simultaneous growth in the number of new therapies, health technology assessment (HTA) agencies are required to produce timelier and more accurate HTA. However, this is a difficult task when the information provided to them stems from short-term clinical trials. This session offered an alternative: real-world data.

A case study

The session was opened by Duane Schulthess, Managing Director, Vital Transformation, who discussed a paper his team recently published in the BMJ, outlining a novel approach to the quantification of the value and effectiveness of new therapies. In Schulthess' example, Chimeric antigen receptor T-cell (CAR-T) therapies were compared to bone marrow transplants as a treatment for acute lymphoblastic leukaemia (ALL).

CAR-T therapy is a new last-resort treatment for ALL. It has been approved for use in the European Union (EU) by the European Medicines Agency (EMA), but due to the high costs associated with CAR-T therapy it is unclear whether it will also be approved by HTA agencies. Because the disease is a rare one, it is difficult to provide the level of data required to assess cost-effectiveness. It is therefore a suitable example for attempting to develop a new, more pragmatic,

methodology for assessing the effectiveness of new treatments compared to usual care. This new methodology involves extracting longitudinal, real-world data from patient records rather than using clinical trials, which allows for access to a greater sample size with longer outcome ranges - even though CAR-T has only widely been available since September 2018. The results appeared to show that CAR-T was less effective than usual care (haematopoietic cell transplant), however this result appears to be confounded by higher levels of disease burden in the CAR-T group. Another important aspect of the methodology was the use of a proxy for relapse, as valid data on the primary outcome itself was not available. Instead, the team looked at prescription patterns of medication commonly used for relapse. However, Schulthess pointed out that the method had been rejected from another journal because the results had not been validated, and that it may also be problematic in the short term for countries that do not have well maintained hospital electronic health records.

The HTA perspective

Anja Schiel, Senior Advisor and Statistician, Unit for HTA and Reimbursement, Norwegian Medicines Agency (NoMA), then gave a crash course in HTA, explaining why what is good enough for approval is not always good enough for reimbursement. Specifically,

there is a big difference between benefits outweighing risks and determining cost-effectiveness. Also, cost-effectiveness must be seen in relation to the respective national health system and not just in the context of a clinical trial. Different countries have different ranges of reimbursed therapies, different budgets and different political pressures and priorities. Schiel went on to highlight some common issues with clinical trials, describing many as 'copy-cats' of other trials rather than being tailored to the drug in question – an approach that works for the regulatory agencies but not for the HTA agencies. Schiel suggested that trials should be informed by already existing, real-world data on the disease. She encouraged the audience to always pose questions such as (i) what data do we need to generate in order to answer the posed questions? (ii) what exactly does the data we have tell us? and (iii) is the data we gathered robust and complete to draw conclusions or allow further research?

The patient perspective

Bettina Ryll, a medical doctor and founder of the Melanoma Patient Network Europe, spoke about why the use of real-world data matters to patients: "It looks very different when you are subjected to evidence-based medicine. You do not want to be the guinea pig. This is so critical – clinical trials are a construct, it is something that is not real. There is equipoise violation, comparison treatment is ineffective, but most ignore this. Everyone wants the trial except the patient." Schiel reinforced this point by adding that current prices "are forcing us to make a clear statement: we should not allow the industry to push through drugs, we need to pull through drugs. We do not want 'me too' drugs. To solve this we need to change the incentive structure."

Bringing everyone together

Nigel Hughes, Scientific Director, Janssen Clinical Innovation, discussed the European Health Data and Evidence Network (EHDEN), an initiative that aims to harness and harmonise large amounts of health data across Europe, through collaboration between healthcare institutions, universities, and industry. EHDEN

will attempt to harmonise research methodologies, infrastructure and organisations, which will facilitate the use of real-world data in many scenarios. Both panellists and members of the audience emphasised that in order for EHDEN to work, data cannot be commercialised. Furthermore, it was highlighted that data needs to be accessible, which is currently not the case.

Here, a debate began about the accessibility of data versus the need for data privacy. One member of the audience mentioned the human genome project and the issues they had with data privacy. Schulthess said he prioritised completeness of data over privacy, while another workshop participant expressed being more fearful of not being able to access their data than of a data breach. Ryll brought some balance into the discussion, arguing that it was the job of the system to protect patient data but also to make it easily accessible to patients at any time. A particular concern is posed by the lack of accessible data of migrants, medical tourists and other vulnerable patients, and the need to protect such data and prevent it from falling into the wrong hands and/or being used for commercial ends.

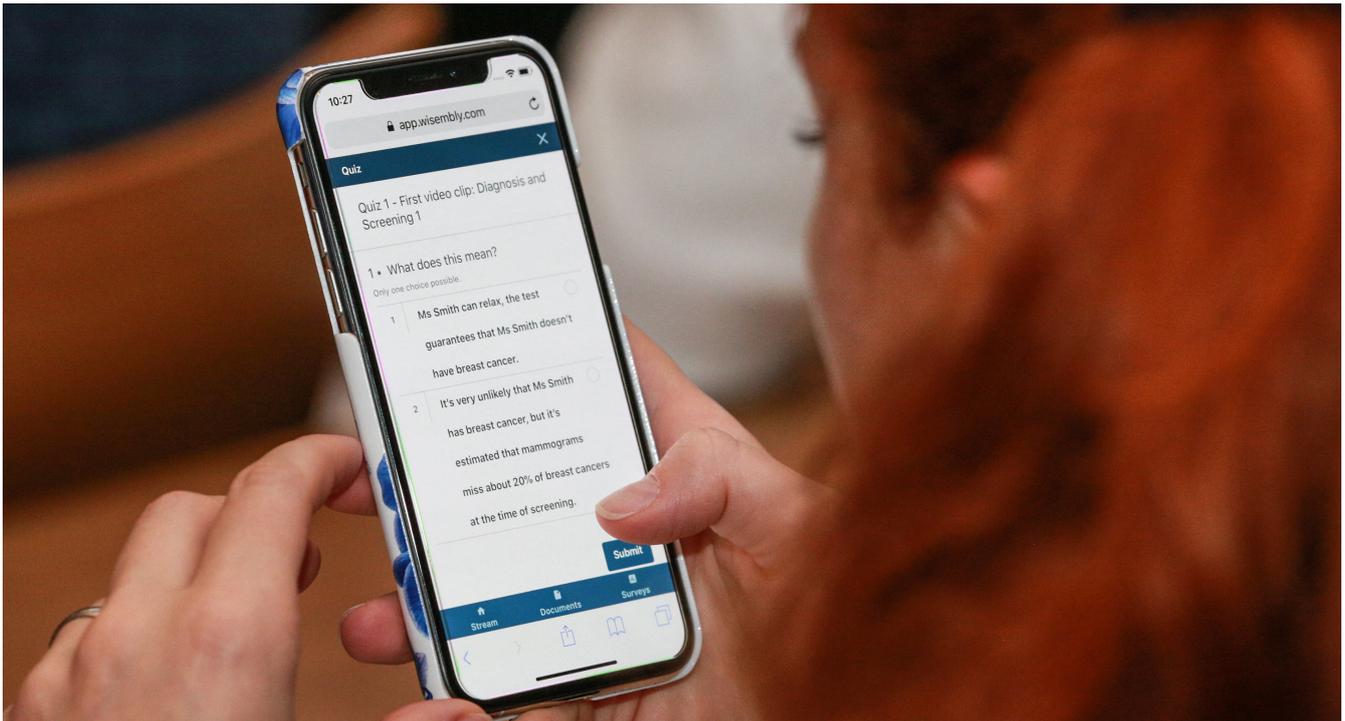
When asked about how the Norwegian HTA agency has incorporated real-world data into their work, Schiel commented "NoMA has increased from one statistician in 2013 to six now. Regulators, HTA agencies and industry have to invest. But it does not matter how many statisticians you have if the data is not good." This sentiment summed up the session: only robust data can provide timely and accurate results and advance and optimise treatments for patients.

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Mind the citizen How health literacy can disrupt cancer care

Organised by The Health Literacy Coalition, sponsored by MSD

Health Literacy Coalition

is composed of:
Standing Committee of European Doctors
European Patients' Forum
Health Literacy Europe
Maastricht University
MSD

“You have cancer.”

A sentence that nobody wants to hear, but if your doctor told you, how would you want her to say it? Would you be able to understand and comprehend any information you hear afterwards? What and who needs to improve so that cancer patients can make informed decisions about their care and disrupt the system?

These questions were on the table in the workshop “Mind the citizen – How health literacy can disrupt cancer care”, organised by the Health Literacy Coalition. Moderator Peter O'Donnell, Brussels correspondent, AGM Health Europe, did not only lead the session, but had also acted as a fictional doctor in preparation of the session, delivering a breast cancer diagnosis to his fictional patient. The short video clips were played throughout the workshop, accompanied by audience polls to check whether the information presented was understood correctly – an exercise not only in health literacy, but also in empathy.

Health literacy – a patient's ability to understand relevant medical information, to analyse and critically assess it, to apply it to their circumstances and make a judgment on their own

situation – has the potential to disrupt cancer care, asserted Kaisa Immonen, Director of Policy, European Patients' Forum. By democratising the relationship between doctor and patient it can empower patients to question their diagnosis and the advice they receive, and thereby potentially shake the healthcare system to its core. Moreover, health literacy means that patients understand their rights, and thereby leads to more equity. With this, almost everyone in the room seemed to agree - but what are the preconditions and possible obstacles?

Doctors need to “speak human”, patients need to build communities

Immonen recalled that for a patient to understand the information they receive doctors need to speak to them in a language they can understand. Vesna-Kerstin Petric, Head of Division for Health Promotion and Prevention of Non-communicable Diseases, Ministry of Health, Republic of Slovenia, added that for this to happen, healthcare professionals need to be health literate themselves. Doctors and nurses not only need to be up to date with current research and able to communicate it effectively, but also understand the system they operate in and guide patients through it as well

as guiding them to their patient community. Tessa Richards, Senior Editor, Patient and Public Partnership, British Medical Journal (BMJ), recalled the frustrating experience of being diagnosed with a rare cancer in 2004, receiving conflicting advice from different healthcare professionals. Back then, there was no community of patients to support each other and exchange the latest information. Through digitalisation, this has changed drastically. Today, patients all over the world can team up and be empowered decision-makers in their own healthcare - if they have the health literacy skills to do so.

A precondition for a productive relationship between patient and care provider, including importantly not only doctors but also nurses, is trust - trust that the medical professional will listen to the patient's wishes and priorities, will not be judgmental, and trust that the patient will follow the medical advice and not let desperation lead them to follow unreliable information from the internet or quacks.

Hospitals, industry and academia need to see patients as part of the team

Patient satisfaction data is mostly seen as “second class”, while patient boards in hospitals are often only consulted to tick a box, Richards criticised. This has to change fundamentally by allowing patients to participate in drug approval processes and to co-create treatments, services and medical curriculums. Patients should not be the object of study, but the teacher, she added. From an industry perspective, Cathryn Gunther, AVP Population Health, MSD, introduced, among other things, an initiative to co-create information leaflets to make sure 95%-99% of patients understand the instructions.

Policymakers need to make health literacy a national priority

Kristin Sorensen, Founder, Global Health Literacy Academy, analysed 31 national cancer plans. Only five of them included

health literacy as a priority, and it was mostly not patients, but individuals or small groups of healthcare professionals that pushed the topic onto the political agenda. Even though health literacy is not yet mentioned in the Slovenian national cancer plan, Petric assured the concept of patient involvement was taken seriously on the political level. The panel agreed that the recently adopted “WHO resolution towards the implementation of health literacy initiatives through the life course” was an important step to raise the political profile of the topic. Translation into national action plans as well as integration into cancer care plans will hopefully follow.

We need to use the current momentum

Improving health literacy in cancer care is not only the “right thing to do”. It has also shown to improve patient satisfaction, treatment outcomes and reduce healthcare costs. It seems to be a win-win for everyone involved, but the implementation is not without problems. The discussion during the workshop revealed several obstacles and open questions: patients have different levels of health literacy and also different potentials to become health literate, calling for the possibility of individual approaches. Will the increased expectations with which doctors are met exacerbate the issue of burnout amongst oncologists? Could the interests of patients and the pharmaceutical industry clash when it comes to the acceptance of risks of treatments? Furthermore, health literacy necessitates technological skills and other competencies that would require the educational system to be adapted, too. To achieve real patient empowerment and the involvement of patients in the design of treatments, studies, hospital management, curriculum development or legislative processes, patient expertise needs to be much more valued and, eventually, translated into compensating patients financially for their engagement. Despite the difficulties, Richards concluded, we do have the momentum now to let health literacy disrupt cancer care, and it is on us to use it.



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Changing the game on health inequalities Why it matters and what we can do

Organised by World Health Organization Regional Office for Europe



Despite overall improvements in health and well-being in the World Health Organization (WHO) European Region, inequities within and between countries persist. The aim of this session was to share recent work on addressing health inequities, The Health Equity Status Report (HESR), published by the WHO European Office for Investment for Health and Development, Venice, as well as to discuss and share good practice examples for reducing the gap in health inequities.

It's time for a change of perspective

The session began with a performance by the Dance Theatre Ljubljana, with dancers representing a family living in poor conditions voicing their daily struggles. The act concluded with the phrase, "Maybe it's time for a change of perspective", a sentiment which was echoed by session moderator Christopher Brookes, Consultant, WHO European Office for Investment for Health and Development, Venice. He introduced the session topic emphasising the need for disruption, particularly disruption of the current status quo. Setting the scene for the subsequent discussions, Brookes quizzed the audience briefly on the drivers of health inequities

and policies to tackle them. Most of the audience were unaware of the main drivers, revealing the extent of work that remains to be done.

Chris Brown, Head of Office, WHO European Office for Investment for Health and Development, Venice; Natasha Azzopardi-Muscat, President of the European Public Health Association (EUPHA), and Fred Freundlich, Professor, Mondragon University, Spain, delivered presentations on the HESR, the role of civil society in addressing health inequities, and the role of businesses in addressing inequities (respectively). This was followed by a plenary discussion with four panellists sharing good practices in reducing inequities: Tracey Cooper, Chief Executive, Public Health Wales; Ales Šabeder, Minister of Health, Slovenia; Anahit Avanesyan, Deputy Minister of Health, Armenia, and Tanel Kiik, Minister of Social Affairs, Estonia.

Yes, we can!

Brown presented the newly published HESR, an ambitious release that calls for change. Not only does it bring forward

evidence of the evolution in health inequities within Europe but also provides possible solutions to be implemented. The report demands a paradigm shift, from the common perceptions that health inequity is too complex to address, to a vision which believes change is required for both human and economic well-being. A 50% reduction in inequities in life expectancy would provide monetised benefits to countries ranging from 0.3% to 4.3% of gross domestic product (GDP) – equivalent to \$60bn in a country of 60 million people. Five essential conditions are needed to create and sustain a healthy life for all: good quality and accessible health services, income security and social protection, decent living conditions, social and human capital, and decent work and employment conditions. Policy actions are needed to address all these five conditions. The HESR also considers the drivers of health equity, namely the fundamental factors to creating more equitable societies policy coherence, accountability, social participation, and empowerment.

Important steps forward have recently been taken, 53 Member States (MS) have adopted a new resolution on reducing health inequities in the form of an alliance, focusing on solutions. The multidisciplinary Health Equity Alliance enables different ministries and governments to ensure that the social values of solidarity, equity, well-being, inclusion, and gender equality are considered and included in growth and development policies. In parallel to this, the Health Equity Solutions Platform is a dedicated mechanism (through live policy innovation sites at country and regional level) for countries and partner organisations to generate and implement solutions to key health equity challenges. Indeed, “Yes, we can, we can make a difference”, stated Brown. It is possible to reduce health inequities in the short term. A 0.1% GDP investment in social protection expenditure, labour market policies, and housing and community amenities can reduce health inequities considerably in four years or less, thus making it achievable during a government’s mandate.

In fact, some countries are already seeing positive results in tackling health inequities. During the session a short video clip was shown highlighting a deprived area of Trieste where health and social systems worked together to reduce health inequities. This was achieved by reaching out to disadvantaged groups to ensure accessibility to health services. Šabeder and Avanesyan both outlined how their countries have worked on improving universal health coverage through stronger primary

healthcare, making sure it is accessible to all population groups in both urban and rural areas. Kiik reiterated the importance of accessibility and explained how Estonia worked around out of pocket health payments (through compensatory means) to ensure affordability. Given that not all people are digitally skilled, he also urged caution about digital solutions, noting they risked increasing health inequities.

The role of civil society

As Brown highlighted, the health gap cannot be reduced unless people are engaged. Governments should work with local communities to identify local issues, devise solutions and build sustainable social action through community development and asset-based methods. This also requires valuing the experience and knowledge of individuals and communities: the ‘lived experience’, maximising the potential of empowering spaces, e.g. youth groups, citizen’s assemblies, and explicitly moving away from stigmatising narratives of disadvantage. According to Brown, the public are concerned about growing inequities: 84% of Europeans believe that reducing inequities should be top of their government’s agenda. Nevertheless, Azzopardi Muscat pointed out that although the public are concerned, most do not truly understand the meaning of the social determinants of health, which results in inequities. She urged NGOs and associations of medical and healthcare professionals to help the public understand what is driving inequities and the increasing trends in noncommunicable diseases (NCDs), such as obesity. Azzopardi Muscat stressed that “Politicians move when the public move”, believing that change is more likely if the general public demand their local and regional authorities take action to address inequities.

Cooper brought forward the example of a transformative approach undertaken in 2014/15 by Public Health Wales. The government began a national, inter-sectoral conversation with the public and policymakers, to identify needs and long-term goals, such as concerns about the environment and climate change, skills and education, employment and housing, and the well-being of future generations. This led to a mandate by the local government, involving various entities identifying what was important to them and their communities. With the outcomes, a health and well-being plan “[The Well-being of Future Generations Act \(Wales\) 2015](#)” was drawn up and implemented, addressing the health gaps present.

The role of business

Freundlich emphasised that democracy in business is also good for health. Going beyond wages and working conditions, he discussed shared ownership of enterprise: how everyone who works in an enterprise should be a part owner of that enterprise. This partnership approach has a positive impact on the work environment, working conditions, the distribution of wealth, and empowerment, and thus helps to improve equalities. As a case study, he referred to the town of Mondragon in the Basque Country where there are many shared ownership companies integrated into a network called the Mondragon Corporation. The companies run supermarkets and banks, produce industrial equipment, provide high-tech consulting services, and provide many other goods and services. Freundlich explained that the county in which Mondragon is located has one of the highest per-capita incomes and lowest poverty rates and levels of economic inequality rates of all the 20 counties in the Basque Country. Moreover, the shared ownership companies average 30-40% fewer industrial accidents when compared to other companies in the Basque Country. "These data are not a coincidence," he emphasised, "it is because of the concentration of these shared ownership companies in this county." How businesses operate clearly impacts inequalities, then. This concept of shared ownership is not such a well-kept secret – in fact 3-5% of employment in the EU is in the social economy. In addition, he explained

that shared ownership could be an opportunity for owners of family businesses who are retiring. Such owners often feel a strong sense of commitment to their local community, sense of loyalty to their employees, and want to leave a legacy rather than see their businesses disappear when they retire. In fact, data shows 15% already consider selling their business to their employees upon retirement – indeed 800,000 businesses in Germany alone face an ownership succession dilemma in the coming year. If these businesses became shared ownership businesses there would be many positive impacts: from keeping businesses alive, to sustaining employment and local tax revenues, to furthering local economic development, to likely having a positive impact on health inequalities.

Closing the health gap

Unless there is understanding from all sectors of society regarding the severity and repercussions associated with health inequities, the health gap is unlikely to be fully addressed. Governments must work with local communities and different sectors in order to identify and address health inequities. Much like the performers at the beginning of the session, civil society must speak out and voice their concerns with authorities to ensure action can be taken, thus thoroughly disrupting the status quo.

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Transforming HIV responses in Europe Focus on disruptive community actions



Organised by MSD and the European AIDS Treatment Group (EATG)

Community action, including activism, advocacy and service delivery, has been extremely important in the global response to HIV/AIDS from the beginning of the epidemic, and it remains a central feature. Despite their crucial role, community organisations continue to be underappreciated and under-resourced in national responses. This session brought together voices from the community, public health specialists and policymakers to explore how and where HIV responses in Europe are failing and to illustrate the role of the HIV community in leading change. Split into three sections, the workshop combined national case studies and interactive breakouts, providing the participants with ideas and potential solutions that could also be applied to other fields.

The perspective of HIV community advocates

Robbie Lawlor, HIV Activist, Act-Up Dublin, Ireland, and Co-founder, Access to Medicines Ireland, outlined the changes in the perception of HIV and of people living with HIV in Ireland. Though a change in prevention campaigns must be greeted, stigma is still firmly present in society and at governmental level. Ireland does not yet reimburse for pre-exposure prophylaxis (PrEP), despite the evidence of its cost-

effectiveness from other European countries. In this situation, civil society organisations have an important role to play. Activists and advocates are engaged in the fight for fully and freely accessible PrEP, as well as for better knowledge and understanding of HIV and its treatments. Lawlor pointed out that all too often when talking about HIV we approach it exclusively as a public health issue, dehumanising people living with the virus.

Irish HIV activists struggle to get fair access to treatment and prevention, yet the situation is even worse in other European countries. The case study of Serbia was discussed by Bratislav Prokic, representing POTENT, the National Center for Sexual and Reproductive Health, Serbia. The low HIV prevalence recorded in the country can be attributed to the lack of attention paid to HIV and to the people living with the virus. In an extremely conservative society, where only 30% of people declare no prejudice against LGBT+, the importance of civil society organisations is not recognised by the government. Volunteers have become responsible for organising prevention campaigns, community testing, and for accompanying patients - with no help from governmental

agencies. Once again, community actions have thereby proven their disruptive power in improving the health of at-risk populations. One of the key actions implemented by POTENT in Serbia is peer support. Peer support practices combine public health concerns with the need for a person-centred approach to HIV, and in doing so improve acceptance and adherence to treatment in newly diagnosed patients. Despite the proven benefits, peer support faces wide opposition from medical staff and public institutions.

The question of drug costs and access was raised by two panellists. Cristiana Oprea, Head of HIV Department, Victor Babes Clinical Hospital for Infectious and Tropical Diseases, Bucharest and Associate Professor, Carol Davila University of Medicine and Pharmacy, Bucharest, as well as Mario Cascio, Chair, Board of Directors, European AIDS Treatment Group (EATG), discussed the structural and economic barriers to treatments in Europe. Although both PrEP and Hepatitis C medications have a strong evidence base, their use has been impacted by high prices and cultural obstacles, even among medical professionals. Thus, many eligible users do not receive these treatments. The LGBT+ population is not the only at-risk group. In Romania, there is a dramatic rise in HIV+ diagnoses among injection-drug users (IDUs) as a result of increasing prevalence of cheap and highly addictive injection drugs. With identity papers being demanded by health services in order for patients to be eligible for reimbursement, IDUs and people who are homeless are often refused necessary care. In this way, structural barriers are affecting the fight against the epidemic. Eastern Europe's institutional HIV responses are failing. Cascio emphasised that we are not doing enough to ensure equal access to treatment, and that little is being done to address the issue of late presentation at diagnosis, which account for 4-6% of new diagnoses every year.

Innovation in public health advocacy

Following the panel discussions, the second half of the workshop featured an even more interactive exchange of experiences and views. A "speed dating" activity was arranged, which allowed for three HIV advocates to elaborate on actions in their own communities. Oprea discussed several HIV and Hepatitis pilot projects that have been carried out in five Eastern European countries. Data has been collected since 2014, leading to new guidelines on healthcare standards and access to treatment that every participating country should be able to follow and apply. Nikos Dedes, Vice-Chair, European

AIDS Treatment Group (EATG), introduced the peer-led PARADIGM initiative: Community-based clinical trials show a higher degree of treatment acceptance than traditional approaches. This was attributed to the fact that they are delivered by people who have experienced many of the same challenges as the service users themselves. Involving service users in the design and delivery of the project has increased its power in relation to the drugs industry. The PARADIGM initiative draws inspiration from the early HIV/AIDS epidemic period, when patients' involvement pushed the industry to supply drugs even before they were fully regulated.

Michael Meulbroek, representing the BCN Checkpoint in Barcelona, Spain, explained how the community centres of his organisation position themselves as an entrance to the health system rather than as an alternative, and are peer-led. Despite ECDC and WHO recognising their central role in providing preventive health services, only a few countries in Europe have implemented community centres in their systems.

How can community action learnings be applied to other fields?

Community action has already proven to be a disruptive power, able to engage public institutions in a process of change. Europe is marked by deep territorial inequalities, with Eastern Europe lagging behind, and most of the Member States not using the instruments provided by the European Commission (EC), as Dedes pointed out. Wolfgang Phillip, Head of Crisis Management and Preparedness in Health, European Commission Directorate-General for Health and Food Safety (DG SANTE), expressed his concern about the under-use of the tools that the EC is offering. An important voice in the final concluding panel was that of Fiona Godfrey, Secretary General, European Public Health Alliance (EPHA), with her call for civil society to join the debate, side by side with medical organisations, in order to exert pressure on policymakers and institutions. Structures like the Civil Society Forum should be revitalised, groups for each condition created, and patient groups should not be put into competition for money or visibility. The role of the EC, as Phillip confirmed, is to ensure that different patient groups can learn from each other. It is by using this shared knowledge that civil society can trigger a change.

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Nobody Left Outside Improving healthcare access for underserved groups

Organised by MSD and NLO



NOBODY LEFT OUTSIDE

Improving healthcare access for marginalised people

“Nobody Left Outside” (NLO) is a collective of organisations working on common challenges that are barring access to healthcare for many marginalised and underserved people, including LGBTI, homeless people, undocumented migrants, people who inject drugs, sex workers and prisoners. This session brought forward the visions and concerns of different stakeholders currently involved in the NLO coalition.

What has been done under the “Nobody Left Outside” initiative?

Firstly, NLO issued a Joint Statement on addressing health inequalities in Europe and improving access to healthcare and targeting of support services through a number of measures. These range from awareness raising to education and training of the health workforce on the health needs of marginalised communities. NLO also devised a checklist intended to facilitate the design of healthcare services based on migrants’ needs, taking into consideration risks, barriers and outcomes. The checklist is structured according to the WHO Health Systems Framework, and has six main sections: service delivery, health workforce, health information systems, financing, leadership and governance, medical products and

technologies. It is a concrete step-by-step document to help service providers improve and adapt their care provision to become more inclusive. Lastly, NLO hosted a photo exhibition to portray the life of people at the margins of society, including their daily struggles and routines, which was also displayed at the EHFG 2019.

Testimonials from the ground

Dinah Bons, Strategic Director, Transgender Europe, ICRSE Board Member, and trained nurse, discussed the main challenges she encountered when working in the field. According to her, difficulties in accessing healthcare - including pharmaceuticals - for marginalised population groups are related to factors such as isolation and poverty, struggles with identity or sexuality, or health issues like HIV.

Moreover, discrimination and stigmatisation in terms of access to housing, education or the labour market are often present. Education and training of health providers to date often fail to acknowledge these complex challenges, which could be improved by e.g. introducing gender specific care and more appropriate mental health services. To promote the required

changes, all of us need to join forces - community initiatives can have an impact.

Mario Cascio, Chair, Board of Directors European AIDS Treatment Group, and member of the Italian network of people living with HIV, then talked about health in prisons - high-risk environments for tuberculosis (TB), HIV and hepatitis. Not only are those admitted to prison more likely to already be infected, but the setting itself can promote the spread of diseases e.g. through unprotected sex or unsafe drug use. Yet prison also offers the opportunity to reach people otherwise invisible to society and often unable to access healthcare services. Cascio presented results from the community project FTL "Free to live well in prisons", that covered more than 1000 prisoners at ten prisons in seven Italian regions. FTL has three main areas of work: assessment of HIV literacy of both inmates and staff via surveys, distribution of condoms and syringes, and education on HIV, including training of prison staff on rapid testing. Educational material on HIV prevention was developed and distributed according to survey results. Although these were unambiguous, several existing risks are ignored by prison management; for instance, condoms are still not readily accessible. Therefore, stronger collaboration between the ministries of health and justice as well as NGOs are needed to find innovative way of working towards sustainable behaviour change.

Denis Onyango, Programmes Director, Africa Advocacy Foundation, named some examples of key healthcare access barriers for migrants in the UK: firstly, the NHS charging policy is hard to understand and has made healthcare unaffordable for many migrants. Secondly, there are fears the NHS may share data with the Home Office, for example if a migrant has

a bill higher than 5000 pounds. This might jeopardise the ability of a person to request a resident visa. To address these issues, Member States (MS) and the European Union (EU) need to work on legislative processes that recognise people in vulnerable situations and provide them with access to the care they need as well as protection from potentially harmful data exchange.

Carina Spak, Facility Manager, AmberMed (Austria), reported how an estimated 27,000-60,000 uninsured people in Austria do not have access to the regular health system, but only in emergency situations. AmberMed aims to restore, stabilise and promote their physical, mental and social health, in cooperation with partners such as the Red Cross. Elena Val, Migration Health Officer, International Organization for Migration (IOM), presented her perspective on integration and access for vulnerable populations. IOM coordinates missions across all European regions and always tries to work closely with both MS and civil society. While not all migrants have problems accessing a novel health system, specific groups of migrants face challenges related to stigma, fears of deportation and legal issues. There is significant evidence showing that community and minority representatives should become more involved in re-designing health and social care services, as they often know best which relevant barriers need to be addressed.

This session showed how underserved communities are not necessarily 'hard to reach' - however services often are. Nevertheless strong, multi-stakeholder collaboration and services designed by marginalised and underserved groups can improve access and equity, while simultaneously helping to achieve the SDGs.



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Can people afford to pay for healthcare? New evidence on financial protection in Europe



Organised by WHO Regional Office for Europe in collaboration with the European Observatory on Health Systems and Policies

Can people afford to pay for healthcare? In Europe, we might have excellent healthcare, but what are the rules? What does universal health coverage mean? Is it really universal? Who pays what and how does this affect patients' and providers' behaviour?

Charles Normand, Professor of Economics of Palliative Care and Rehabilitation at King's College London, asked participants uneasy questions in this afternoon session organised by the World Health Organisation Regional Office for Europe with the European Observatory on Health Systems and Policies.

It was an occasion to present data on unmet medical needs and personal financial hardship for 24 countries in Europe collected and analysed by the WHO Regional Office for Europe. The new evidence supported the discussion and pushed the panel to advance the debate from the problems around the complex systems of co-payment for healthcare to possible solutions on how to reduce financial hardship of vulnerable population groups.

"Who? What? And how?", Tamas Evetovits, Head of the WHO Barcelona Office for Health Systems Strengthening, started his presentation by asking:

- Who are the people experiencing financial hardship in terms of using health care services?
- What kind of services require out of pocket (co-) payments? and,
- How to make improvements?

Universal health coverage (UHC), Evetovits explained, is not as universal as proclaimed. Even in countries where UHC is provided, certain health care services require co-payments that patients have to pay out-of-pocket (OOP), while some other services are not included in the benefits packages at all. As a result, people seeking health care they need and should be entitled to might experience financial hardship - they either suffer unmet needs or must prioritise healthcare over other basic human needs. Consequently, it is important to distinguish between UHC with and without financial hardship.

The UN Sustainable Development Goals (SDGs) could be achieved easily if we looked only at population coverage but

as the WHO representatives noted, we are missing information on access to quality healthcare services, unmet needs and financial risk protection. The new WHO report presented during the session ([WHO Regional Office for Europe, 2019](#)) defines that catastrophic health spending occurs when more than 40% of a household's financial capacity, after they pay for basic needs, is spent on healthcare. The devastating effects of OOP payments are also captured by using a relative poverty line instead of the absolute poverty that is often used at the global level.

The new metrics introduced by WHO reflect the realities on the ground more accurately. To compare, the SDG framework uses a 10% threshold, suggesting that rich households are lacking financial protection, which does not make sense. Similarly, poorer households spending less than 5% of their household budget on health care did not reach the 10% threshold and, therefore, were not considered as experiencing financial hardship. Jonathan Cylus, Economist at the European Observatory on Health Systems and Policies further explained that WHO uses a refined method for country-specific analysis by deducting basic needs like food, rent and utilities from household income and introduces a flexible threshold according to household budgets.

All in all, households are more likely to face financial hardship the more patients are exposed to OOP payments. Needless to say, poor households are most affected by OOP payments. In most countries, the OOP spending on outpatient medicines and dental care are the main drivers of financial hardship, especially for the poorest households. This information is by no means new, as the European Patient's Forum (EPF) survey ([European Patient's Forum, 2016](#)) on patients' access to healthcare shows that only 22% of respondents never had difficulties to pay for necessary care. Kaisa Immonen, Director of Policy at EPF said that affordability of care and medicines was an inbuilt component of this survey carried out in 2016.

Reasons to focus on UHC and how to reduce the burden of financial hardship were delivered by Sarah Thomson, Senior Health Financing Specialist at the WHO Barcelona Office for Health Systems Strengthening, in the form of six main policy messages:

1. Identify gaps in coverage. Not only the level of OOP payments but also the distribution across society. What does the benefits package include? Are user charges

covered?

2. Identify weaknesses of your co-payment policy design. Are poor people exempt from co-payment? Are there annual cap mechanisms? Are fixed co-payments, percentage payments or a mixture of both used in the national context?
3. Use exemptions to protect those in need. There is no economic justification for making vulnerable people or regular users pay for healthcare and make them even poorer. Exemptions for poor people work! As an example from Latvia demonstrates: during the financial crisis in 2008, very poor patients were exempted from payments. Those who were exempt were more likely to return to work. In 2012 the exemptions were abolished, and levels of impoverishment increased.
4. Use caps to protect everyone: cover all co-payments, ideally link the cap to the household income. Monitoring the cap is key. For example, in Czech Republic the cap was lowered because not many were reaching it.
5. Avoid percentage co-payments, as they expose people to health system inefficiencies.
6. Think about people who need health care when designing the system. Protect people, not services or diseases. Keep coverage systems simple, people need clarity. Minimise bureaucracy around the process.

To understand the complex co-payment systems on the ground better, the audience learnt about changes made in recent years in Estonia presented by Triin Habicht, WHO consultant and former Head of the Department of Health System Development at the Ministry of Social Affairs in Estonia. Stefan Eichwalder working in the Cabinet of the Minister of the Austrian Federal Ministry of Labour, Social Affairs, Health and Consumer, introduced the system in Austria.

Estonia used a combination of fixed co-payments per item, percentage co-payments and internal reference pricing (IRP): a fixed co-payment of 3,19€, percentage co-payment of 50% and IRP OR a fixed co-payment of 1,27€, percentage co-payment of 25/10/0% and IRP. Children younger than four years, adults older than 63 years, pensioners and people unable to work were eligible for exemption. Moreover, when exceeding a threshold of 300€ and 500€, 50% or 90% of co-payments were covered by health insurance. However, there were no automatic mechanisms neither for exemption from co-payments nor for additional reimbursement. Hence, only

around 3,000 people applied and, thus, benefited from co-payment regulations in place. Consequently, Estonia adjusted its system by introducing a fixed co-payment per item of 2,50€, percentage co-payments of 50/25/10% or 0% and IRP. Moreover, thresholds for additional reimbursement were reduced to 100 € and 300€ and an automatic mechanism for eligibility was introduced. These changes resulted in 134.000 people eligible for additional reimbursement or exemption – and on top of that, they were almost budget neutral.

Austria uses a combination of fixed co-payments (6,10€) and a cap of 2% based on the annual income, automatically exempting eligible people. Additionally, there are several co-payment regulations for specific products and health services, varying between different providers of statutory health insurance. However, better targeted policies are necessary to reduce user charges.

Speaking from the European Commission's perspective, Martin Seychell, Deputy Director-General of DG SANTE, stressed that the health sector should take advantage of the

EU macro-economic policy cycle, the European Semester. The Semester's most useful contribution is looking at what exactly could be done in each Member State to address macroeconomic imbalances and social equity, Seychell added.

To advance the state-of-the-art of financial protection in Europe, speakers and participants concluded, further qualitative impact assessment is needed. It should explore how changes in co-payment systems for healthcare affect poor people, always considering what is included in the service basket. Furthermore, it will be essential to add a human story to health data – and to make use of all policy instruments available to tackle financial protection, nationally and on the EU level.

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European alcohol policies Rethinking and strengthening implementation



Organised by WHO Regional Office for Europe, European Health Forum Gastein, EU-HEM, IOGT-NTO and International Youth Health Organization, supported by the Republic of Slovenia

In European countries the consumption of beer, wine and spirits seems to be part of the social fabric of society. In this context, it is often easy to underplay and disregard the health and social damage caused directly or indirectly by alcoholic beverages. However, harmful intake of alcohol contributes annually to three million deaths worldwide - 5.3% of all deaths. It is also a casual factor in more than 200 disease and injury conditions. Alcohol consumption in the WHO European Region remains the highest in the world, resulting in one million deaths per year. Delivering welcome remarks, Clemens Auer, President, European Health Forum Gastein, and the session moderators Bente Mikkelsen, Director of the Division of Noncommunicable Diseases and Promoting Health through the Life-course, WHO Regional Office for Europe, and Siegfried Walch, Management Center Innsbruck, all called upon European countries to take a leadership role in preventing and reducing alcohol consumption, stating that it was time to rethink European policies and regulations. Too often, political commitments are made but policies lack effective implementation to drive a social shift in people's attitudes towards alcohol.

Evidence, tools and WHO best buys

Carina Ferreira-Borges, Programme Manager Alcohol and Illicit Drugs, WHO European Office for the Prevention and Control of NCDs, set the scene with an overview of the evidence and tools currently available. Even though alcohol consumption has reduced in the WHO European Region, differences in total alcohol per capita consumption remain across countries, in particular between north-eastern European countries and EU Member States (MS). There are also significant differences between population groups. Data from 2016 showed that more than half of male drinkers aged between 15 and 64 engaged in heavy episodic drinking, underscoring the need for action to address this public health issue.

Harmful use of alcohol is specifically mentioned under the Sustainable Development Goal (SDG) health target 3.5 on substance use. Beyond the negative impacts on health, it further brings significant social and economic losses to individuals and society at large. Countries have committed to accelerate progress through many strategies and resolutions, most notably as part of the Global Strategy to reduce the

harmful use of alcohol ([World Health Organization, 2010](#)). We know that alcohol policies work, as demonstrated to participants by the example of Russia where alcohol control policies led to reduced alcohol consumption while life expectancy increased. The most cost-effective actions, also called the 'best buys', to reduce the harmful use of alcohol are increasing taxes on alcoholic beverages (pricing); enacting and enforcing bans or comprehensive restrictions on exposure to alcohol advertising, and restrictions on the physical availability of retailed alcohol. However, these best buys are not widely implemented in European countries. Among the main barriers are a lack of political will; lobbying by the food and drink industry; lack of cross-sectoral collaboration; cultural resistance, and lack of policy enforcement.

Policies matter!

How these barriers could be overcome was widely discussed during the first panel of the session. Eva Jané-Llopis, Director, Health SDGs and Social Innovation Programme, ESADE Business School, pointed out three main aspects: to overcome strong lobbying efforts by industry who still question the substantial evidence available; to mobilise social support to drive change, and to monitor the implementation of policies. The case of Sweden, with Systembolaget (a government-driven business model) operating as the sole alcohol retailer in the country, served as an example of a country where WHO's best buys have been successfully implemented.

Johan Lindblad, Public Affairs Director, Systembolaget, underscored the importance of having high population health literacy about the negative consequences of alcohol consumption. Vesna Kerstin Petric, Head of Division for Health Promotion and Prevention of Non-communicable Diseases, Ministry of Health, Slovenia, reflected on challenges encountered to drive alcohol policies in Slovenia, in particular related to the strong lobbying efforts by the industry, and the importance of strengthening NGOs to counter this. Andrej Martin Vujkovic, President, International Youth Health Organization, stressed that particular attention needs to be placed on the youth. It is important to include young people in policy-dialogues with governments, to raise awareness amongst young adults of the harmful effects of alcohol, and to explore alternatives that can be offered to them to ultimately protect future generations from harmful drinking.

How to enact meaningful change in the social mindset around alcohol?

The session participants were invited to break into small groups to consider ways to address three specific challenges around alcohol policy implementation.

1. How to overcome barriers for implementing WHO best buys?

Participants thought that there should be greater public awareness and acceptance of the best buys. To achieve this, they considered that the public needs to be better educated on the harms of alcohol consumption and develop an understanding of the tactics of the alcohol industry in influencing political processes and steering the public discussion on alcohol in a direction that favours its business. On a policy level, it is imperative that we are explicit about the link between alcohol consumption and many other SDGs. Here, we need to consider the drivers of alcohol consumption, and investigate the social determinants of drinking and how to address or redirect these.

2. How to create an effective forum that avoids conflicts of interest?

Instead of a "forum", participant discussions concluded, we should be aiming to build a robust "coalition" with a clear end goal: no harm from alcohol. This goal should be supported by two broad action areas: 1) reducing alcohol consumption, and 2) reducing harm caused by consumption. In order to maintain transparency, conflicts of interest must be closely monitored, and this would necessarily exclude alcohol industry involvement. Questions remained outstanding on which groups to involve and how to fund such a coalition.

3. How do we shift the social norms around alcohol consumption and mobilise public support for transformative change?

In order to reduce alcohol consumption, it is vital that we understand the reasons behind it. Humans have consumed alcohol for thousands of years, and so addressing consumption is not a straightforward task. To the extent that alcohol consumption is a learned behaviour, reduction campaigns need to be disruptive in a variety of ways. Campaigns aimed at reducing consumption need to focus on educating the public, rather than creating a "shaming and blaming" culture. Restricting marketing and limiting the availability of alcohol in the public space are good options, participants thought.

Practical examples included restricted the opening hours of licensed premises; reducing the size of alcohol measures/ bottles, and preventing alcohol from being sold at events, with the venues being compensated for the commensurate reduction in income. Encouraging and empowering grassroots movements was also considered key, rather than relying solely on paternalistic government policies. Individuals and civil society should focus on promoting the message that social interaction doesn't have to include alcohol, which should go hand-in-hand with encouraging the promotion and marketing of healthy alternatives to drinking (e.g. other non-sugary beverages or non-alcoholic social interactions).

Shifting social norms

A subsequent panel discussion considered the outcome of the group discussions. Jan Pelozza, Co-founder, No Excuse Slovenia and Board Member, International Youth Health Organization, pointed out that when it comes to alcohol, demand is driven by supply, and so we should advocate for comprehensive alcohol policies. Reflecting on the shifting social norms around alcohol consumption, Kristina Sperkova, International President, IOGT International, stated that there are many people who are already choosing not to use alcohol. In a study in Sweden, for instance, 80% of alcohol users said they would prefer more alcohol-free environments while 60% of people would like to live alcohol-free but don't due to other pressures. Disrupting the norm is therefore very important and requires brave individuals to stand-up and advocate for

change, much like Greta Thunberg is doing for the climate crisis.

A clear message

Ilona Kickbusch, Founding Director of the Global Health Centre, Graduate Institute of International and Development Studies, Geneva, emphasised that alcohol is much more widely available now than previously, a trend observed in other parts of the globe as alcohol is becoming a consumer product. Instead of entering the "harm dialogue" preferred by industry, we should focus on addressing the commercial determinants with a clear public health goal of reducing overall consumption. Alcohol is not a normal commodity, and so it needs to be exposed and dealt with using a different approach. Therefore, the challenge of alcohol consumption needs to be addressed in a similar way to tobacco consumption: we need a clear, strong and unified message, supported by strong collective leadership.

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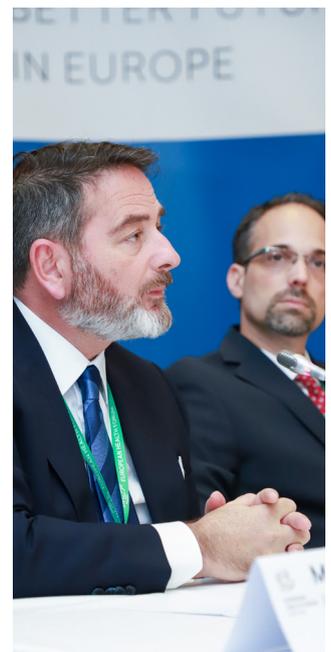


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