



EUROPEAN  
HEALTH FORUM  
GASTEIN

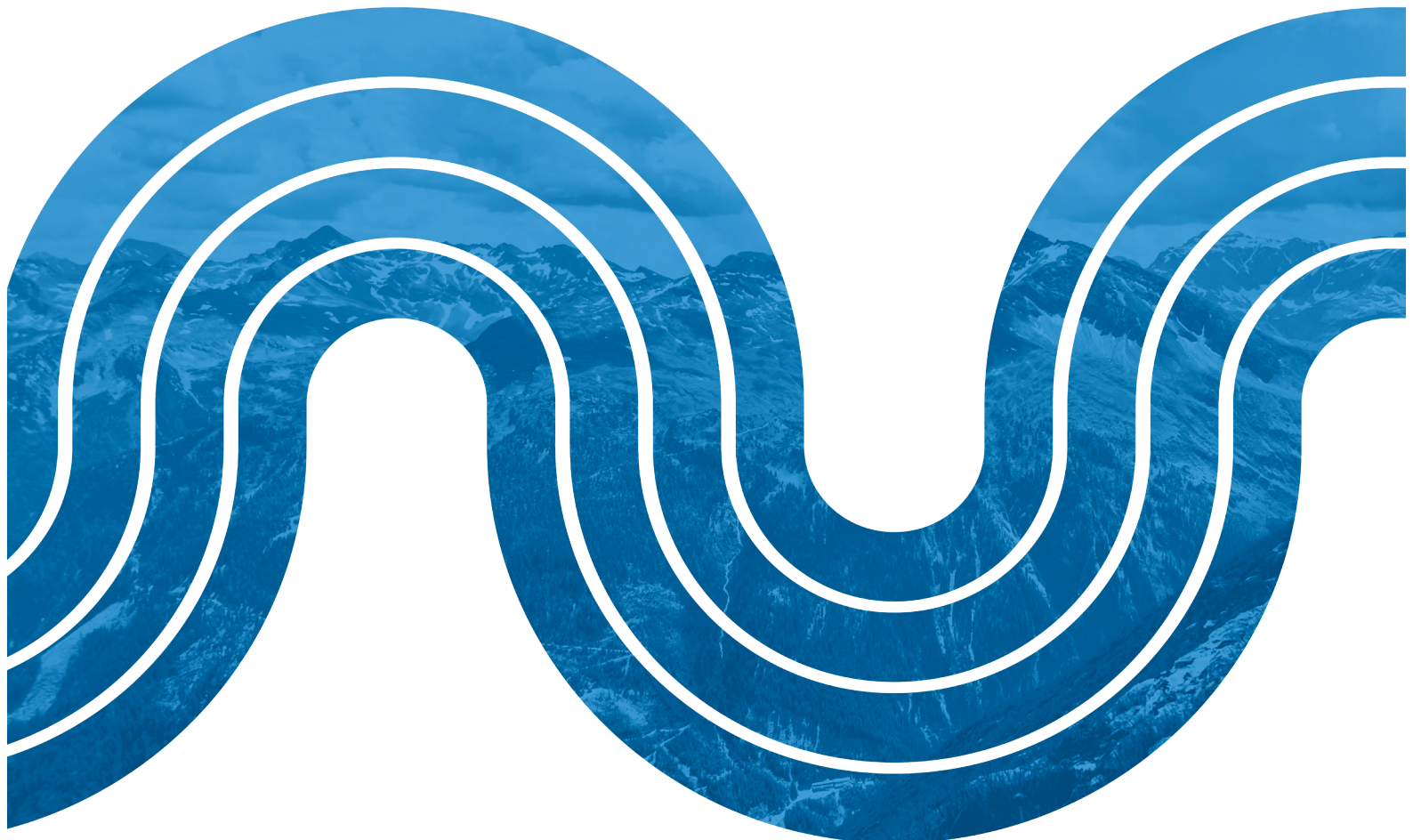
3 - 5 OCTOBER 2018

21ST EUROPEAN HEALTH FORUM GASTEIN

# Health and Sustainable Development

Bold political choices for  
Agenda 2030

Conference Report



# Lists of abbreviations

AUD	Australian Dollars
DG	Directorate General
DG GROWTH	DG Internal Market, Industry, SMEs and Entrepreneurship and Services
DG SANTE	DG Health and Food Safety
EC	European Commission
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
FCTC	Framework Convention on Tobacco Control (UN)
GP	General practitioner
GBP	United Kingdom Pound Sterling
HCP	Healthcare professional
HIA	Health Impact Assessment
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
RWE	Real World Evidence
SDGs	Sustainable Development Goals
SGPP	Steering Group on Promotion and Prevention
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



# EHFG 2018 report

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Taking on the Presidency of the organisation in 2017, my vision was to expand the Forum's role in translating knowledge between experts and policymakers from all sectors. In 2018, Gastein has made new strides towards bringing fresh impulses and actors to the debate on the future of health in Europe and moderating the dialogue between the health sector and its peers, so that an effective intersectoral agenda for health, well-being and sustainability can be pursued.

From the beginning, the EHFG has worked to involve and unite its four pillars – public and private sectors, civil society, science & academia – in a frank but fair dialogue on health policy development by providing an impartial and inclusive platform for debate.

Gastein remains the foremost European health forum to actively engage in candid but balanced conversations that invite all relevant stakeholders to the table. We will continue to strive for new frontiers in outcome-oriented discussions that inspire bold action, exploring future-facing topics in politically turbulent times and offering space for controversial debates and out-of-the-box thinking from which the seeds for creative restructuring and disruptive ideas may grow.

I would like to take this opportunity to thank our partners and session organisers as well as all of our board and Advisory Committee members and the EHFG team for their support and contribution to this years' edition. We are delighted to present to you the report on the 21st European Health Forum Gastein and hope to welcome you to next year's edition from 2nd – 4th October 2019.

**Clemens Martin Auer**

President, European Health Forum Gastein

# About us







## European Health Forum Gastein

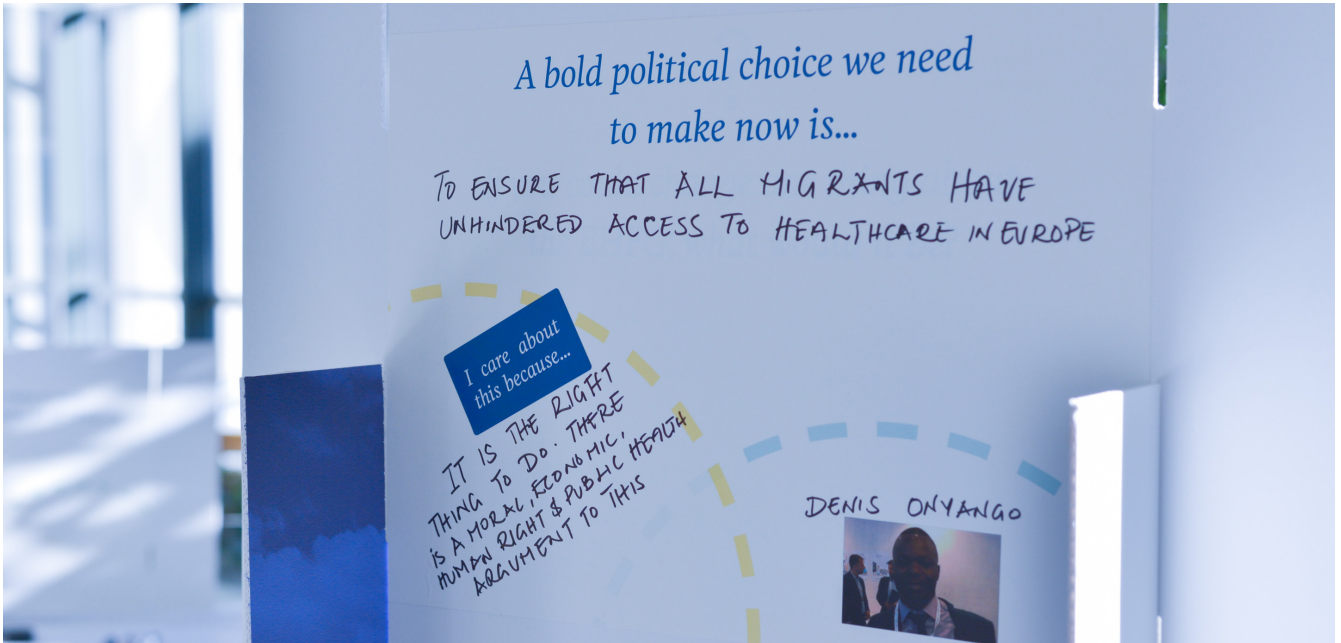
*The European Health Forum Gastein (EHFG) is the leading annual health policy event in the European Union. With its wide-ranging three-day programme, the Forum offers an unparalleled platform for decision-makers in various fields of public health and healthcare.*

The European Health Forum Gastein was founded in 1998 as a European health policy conference with the aim of providing a platform for discussion for the various stakeholders in the field of public health and healthcare.

Since then the EHFG has developed into a key annual event, bringing together, politicians, senior decision-makers, representatives of interest groups, and experts coming 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.

The EHFG further considers the vertical organisation of societies and the EU by integrating regional, national, European and international levels and thus facilitating the exchange of views and experience amongst key actors and experts from the 28 EU members and the EEA countries, but also from the rest of the 52 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. In that regard the Forum can be considered as a pilot project and benchmark for any Commission civil society consultation process.

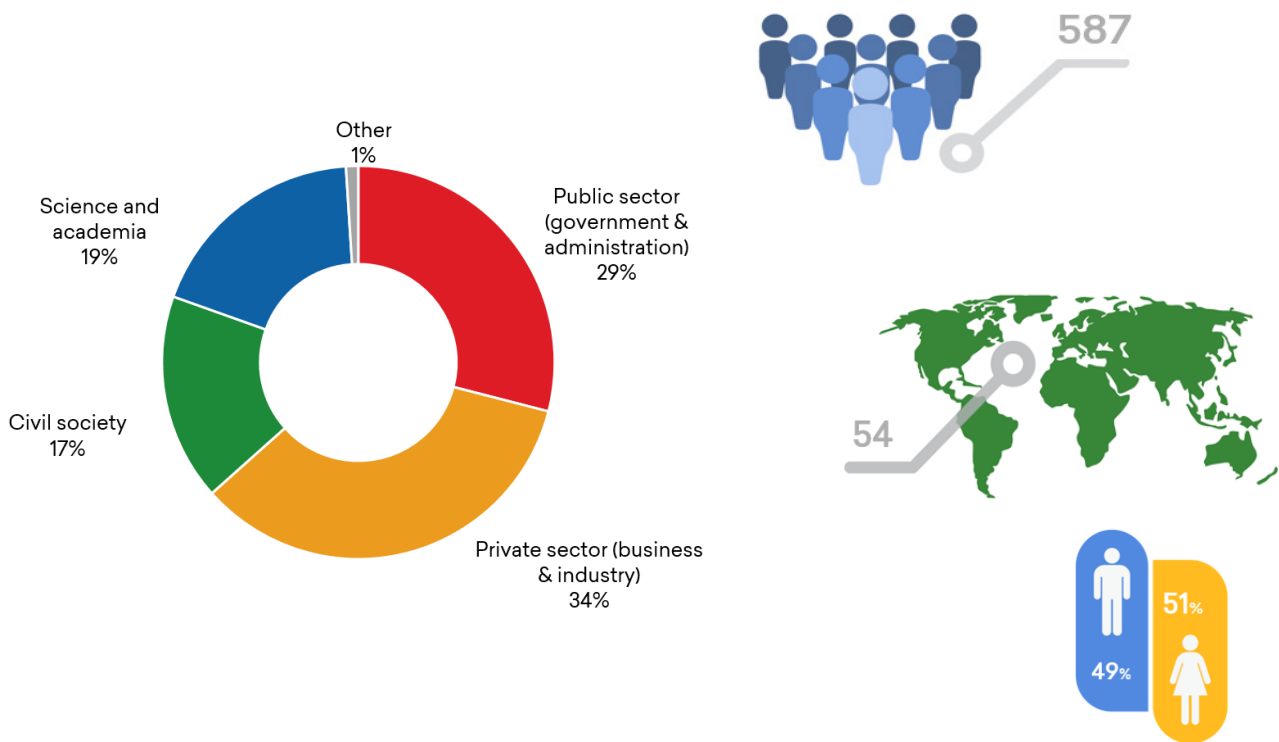




## EHFG 2018 in numbers

Gastein brings together the worlds of politics, academia, private sector, and civil society in a setting where everyone is equal. Over 500 leading experts participate in the annual conference - the unparalleled mix of participants is especially critical to the success of our event.

### Breakdown of participants



Programme  
EHFG 2018







## Opening Plenary: Health In Europe – Let's Think Big!

Organised by European Health Forum Gastein



The European Health Forum Gastein 2018 Opening Plenary started with a challenge to think big, bold and brutally practically to improve health in Europe and reach the SDGs. A new bold direction is needed to reassure a European electorate that is worried about the European single market, employment policies, protection of external borders, and immigration policies. In a keynote speech, Clemens Martin Auer, President, EHFG, argued that health is wealth and despite our advances, our success stories are closely linked to the health of our societies – an EU that isn't strong on health threatens both cohesion and the success of the European single market. He suggested that health needs a new narrative if it is to assert itself in the face of the presumed and real

diktats of globalisation, security and consumption. The UN with the SDGs have started to pave the way in this regard by providing a valuable, socially-oriented model. We need now to recognise the impact of market forces on health, in positive or negative terms, be bold and move forward, with a strong footing for health on all political competence levels.

Peter C. Smith, Emeritus Professor of Health Policy, Imperial College London Business School, argued that the health system can contribute to reducing the fiscal sustainability problem (maintaining the public finances at a credible and serviceable level over the long term) across Europe in at least three ways: increasing labour market participation by

addressing disability and chronic diseases; providing long-term care for chronic disease sufferers to reduce the need for informal care (carers); and impacting pensions (increasing the pensionable age is not enough as people need to be healthy to be productive). On the other hand, the health sector itself needs to understand that its mission is far beyond healthcare and science. The health of people in the EU is not only dependent on our healthcare, our healthcare workforce, research and science. This message was reinforced in a video from Vytenis Andriukaitis, European Commissioner for Health and Food Safety: out of 17 SDGs, 12 are closely related to nutrition and health, he emphasised. The goals recognise the interconnected nature of development and promote the active involvement and partnership of all sectors and actors globally. In other words, sharing responsibility for health across sectors is crucial, and areas such as food, transport, housing, environment and education have an enormous impact on our health and a key role to play in maintaining or improving the health of future generations.

It was clear from the panel discussion that MS representatives present (Austria, Finland and Estonia), the EC and the WHO are all committed to thinking big and working through intersectoral approaches. Liisa-Maria Voipio Pulkki, CMO and Head of the Management Support Unit, Ministry of Social Affairs and Health, Finland, explained how the HiAP paradigm has advanced in Finland since the last Finnish Presidency: it has become a politically accepted concept and a number of legal actions have been put in place to support this. Municipalities have a responsibility to report annually on multi-sectoral health promoting activities, with more comprehensive reports every four years. The attention paid to Health Impact Assessments (HIA) by other ministries such as trade, transport and agriculture when formulating legislation has also significantly improved. Voipio-Pulkki also described how a recently drafted new strategy for the Finnish Ministry of Health and Social Affairs had been written in a completely different style and using different language, to make it more accessible and understandable to stakeholders outside the health sector, such as colleagues in other ministries and civil society. Joint working on HiAP is also in evidence when preparing for new governments: Finland is likely to hold parliamentary elections in April 2019, so ministries are already working together to shape a final document of ideas for policies to suggest to the incoming government that transcend the different sectoral silos.



Estonia is thinking big in different ways. Riina Sikkut, Minister of Health, Estonia, explained how her Government has recently set a target to “sequence” the DNA of over 10% of the population to gain insights that will improve health outcomes and strengthen diagnostics and prevention. Estonia is also leading the way in terms of innovative digital solutions in healthcare. One recently introduced innovation described by Sikkut concerned the tracking of heavy pharmaceutical users eligible to receive subsidised prescriptions. With a new digital solution all eligible users received the subsidy, compared to only a third who applied for it when the form was paper-based, demonstrating well how digital solutions do have the potential to reduce health inequalities.

At the EU level, Martin Seychell, Deputy Director-General for Health and Food Safety, EC, emphasised the importance of creating practical tools to help citizens tackle the obstacles that they face. For example, the EC has organised supra-national hospital networks to take advantage of shared knowledge on rare diseases and enable patients to be supported in their home countries, explained Seychell, who also commented that he was inspired by the current extent of cross-European collaboration between MS, pointing to the

example of pandemic vaccines, ERNs, HSPA, ehealth and HTA. However not everyone is getting a fair deal in the Europe of today, and we have to dig behind the numbers when it comes to underserved populations, Seychell advocated. Behind the statistics we have widening inequalities, and this is the root cause of a lot of the political and social problems that we are facing. The underserved have to be identified as they have particular needs and require specific forms of assistance – they require tailor-made interventions and won't be reached by population-based strategies.

Some European-level initiatives offer significant hope for improved future well-being, said Freek Spinnewijn, President, Epha. For example, while the new European Social Pillar is currently just a declaration, if effectively implemented it has huge potential for advancing public health in Europe. But there needs to be more political urgency for action on key social issues that are important determinants of health, such as housing, he stressed. Thinking about practical ideas for improvement, he pointed out the artificial distinction within the EPSCO Council between health and social affairs ministers and their meetings. They are responsible for overlapping issues which would deserve a pragmatic, joint approach to harvest synergies, he suggested.

Zsuzsanna Jakab, Regional Director, WHO Europe outlined how the WHO Regional Office for Europe is thinking big by working on a roadmap for Europe to reach its SDG targets. She also asserted that despite an abundance of evidence we are still not doing enough to implement action (including but not limited to the topic of NCDs) which requires strong leadership at the highest political levels, interconnected policies and the protection of (EU) values. "The big elephant in the room is fragmentation", said Jakab, highlighting once again the importance of intersectoral collaboration.

Concluding the panel discussion, the participants offered some final thoughts. Riina Sikkut advocated small steps for incremental change on the topics discussed in Gastein this year. Liisa-Maria Voipio-Pulkki expressed a desire to encourage greater participation in the EHFG 2019 from the Nordic countries, hoping to promote the event during the Finnish Presidency in 2019. Zsuzsanna Jakab highlighted that we know what we need to do and that involves prioritising prevention, solidarity and equity related issues, with the SDGs offering a good framework for us to do this. Martin Seychell said

that we are living in a defining moment for health, but we have to start thinking more like investors, thinking systematically, funding priorities in the right way, and not being prisoners of the past where old strategies may no longer serve us well. Leadership, strategy and resources are required – we have all three but we haven't always utilised them effectively together, and the time is right to do this, he stressed. Clemens Auer had the final intervention and implored conference participants to write a letter to their Prime Minister or prospective candidates in the EP elections to keep health high on the political agenda.

The European Health Award 2018 ceremony followed the panel discussion. The prize was awarded to The European Cancer Patient's Bill of Rights (BoR). This initiative was developed to address cancer inequalities across Europe. Launched in the EP, the BoR has been a catalyst for change, underpinning an equal partnership between cancer patients and healthcare professionals to deliver improved outcomes for European citizens. Accepting the Award on behalf of his colleagues and on behalf of all cancer sufferers and cancer patients in Europe, Mark Lawlor, Professor, Queens University Belfast, lauded the project's equal partnership between cancer patients, healthcare professionals and scientists, and said the prize money would be focussed on addressing cancer inequalities specifically in Central and Eastern Europe.

Written by B el ene Podmore and Louise Boyle

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**Photo impressions**

**Blog post**





## Thursday Plenary

### Talking so you're heard - making the case for investment in health

Organized by the European Health Forum Gastein

in partnership with Regional Office for Europe and European Observatory on Health Systems and Policies



Following this year's overarching conference theme of thinking big, being bold and brutally practical when it comes to health and sustainable development, this session set out to discuss the economic and societal value health creates and explore ways to better communicate this asset across sectors. A reciprocal understanding of and ongoing dialogue between decision-makers from the health and financial sectors is key to securing sustainable investment in health and strengthening and improving health systems. Such a common understanding between sectors requires correcting the health system's image of being a 'black hole' devouring and wasting resources. Instead, the debate needs to move towards emphasising the great value health systems create and the tangible returns on investment they can yield.

#### Finding a common language between health and finance is key

In a humorous video message, Geert van Maanen alternated between his former roles as Secretary General at the Dutch Ministries of Health and Finance and depicted the budget

negotiations of a fictitious funding request from the Ministry of Health to the Ministry of Finance. Despite its comical connotation, the video raised the question of what it really takes to make a successful case to financial decision-makers for investing in health: is it about bringing more evidence to bear or rather about the way the health sector communicates its funding requests? While there are no simple answers, it seems that acknowledging each other's perspectives as well as trying to create co-benefits for both parties are essential for fruitful cooperation.

#### Spending on health as a contributor to inclusive economic growth

In his introductory speech, Hans Kluge, Director of the Division of Health Systems and Public Health, WHO Regional Office for Europe, used the 10-year anniversary of the Tallinn Charter to remind us of its core principle: the ability of health system spending to contribute to inclusive economic growth, thus creating a win-win situation for health and finance. In order to create such win-win situations, four essential fiscal and

political points need to be considered. First, evidence-based, transparent and efficient spending of monetary resources by balancing the short- and long-term returns on investment. Second, the promotion of inclusive economic growth by acknowledging health professionals' dual function as workforce keeping other workers healthy. Third, the need to prove that investment in health can contribute to societal well-being by moving beyond traditional measures – such as GDP – to multidimensional ones. Lastly, the ability of health to promote fiscal sustainability by keeping an ageing population healthy and, as such, reducing health and social care expenditures. Spending on health is therefore not to be seen as a cost, but rather as an investment.

### **Fiscal sustainability as the precondition of economic sustainability**

Opening a lively panel discussion, Wilhelm Molterer, Managing Director, European Fund for Strategic Investments and former Austrian Finance Minister and Minister of Agriculture, emphasised the importance of fiscal sustainability as the basis for economic sustainability. As the main responsibility of a finance minister is good stewardship of public resources, the careful balancing of different sectoral budgets is essential. Expenditure on health, or any other sector, needs to be seen in light of available revenues. An increase of expenditure in one sector leads to decreased financial resources for another. The health sector needs to continuously evaluate whether it is providing the right services and whether resources are being wasted or efficiency gains can be made throughout the process, said Martti Hetemäki, Permanent Secretary, Ministry of Finance, Finland. The evaluation of the efficiency of health interventions, based on the latest available national and international evidence, needs to serve as the basis for this decision-making process.

### **Evidence is crucial, acknowledging the political economy just as important**

Sharing her experience as State Secretary for Health at the Ministry of Health in Romania, Corina Silvia Pop stressed the fact that current political realities always play a major role in decision-making, even when there is evidence for the benefits of a specific health-related investment. Failing to acknowledge the political economy when trying to evoke investment in health will most likely lead to a failure in doing so. Upcoming elections, for instance, might lead to innovations being favoured over prevention as they promise short-term effects

and are therefore more likely to lead to votes than prevention programmes that show their effects only over a longer period of time.

### **Getting the private sector on board: simultaneous necessity and risk**

Given the significant challenges related to ageing populations, the private sector could be an important and valuable partner. PPPs could become an ever more important supporting source of funding for profitable health investments in times of growing health expenditures. While acknowledging their great potential, Jennifer Dixon, Chief Executive, Health Foundation, also warned of the possible vested interests of powerful private players. Furthermore, she decried the lack of leaders making the case for investments in integrated care and social determinants of health. The UK is now trying to tackle this problem by ensuring that hospitals take greater responsibilities to address the wider determinants of health.

Zsuzsanna Jakab, Regional Director, WHO Regional Office for Europe, concluded the plenary by linking the discussion back to this year's EHFG main theme and emphasising that health is at the centre of sustainable development. Health is inseparably linked with the social sphere and environment. Therefore, it should be discussed at the highest level of political decision-making. Following current projections, increasing health expenditures will outgrow the predicted trajectory of budget growth in the next decade. The only solution to tackle that upcoming deficit is to make populations healthy, prove the value for money of health systems and thus unleash the health system's potential to contribute to fiscal sustainability.

Written by Patricia Dundler and Fabian Schrogl

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## Closing Plenary

### Commercial determinants of health & the global financial markets

Organised by European Health Forum Gastein



In the health community, it has become well accepted that action on the social determinants are required to address health inequalities. However, the commercial determinants of health have frequently been overlooked, with the role of global capital flows and financial investments and their impact on health largely underestimated and ignored. Given that a significant share of the global food, beverage and tobacco industries are owned by institutional investors, it is high time for the public health community to step-up and address issues around the responsibility of investors in relation to the commercial determinants of health. There is a need for a more holistic approach, and it is necessary to think in broader terms. Thus, the promotion of health should not be the exclusive responsibility of the health sector, but it should arguably involve other actors aiming to create synergies and convergences between sectors to improve the overall health of the population. Clemens Auer, President, EHFG, opened this plenary, which was moderated by Martin McKee, Professor of European Public Health, London School of Hygiene and Tropical Medicine.

#### Tobacco-free finance

In recent decades there has been growing interest in ethical investments. Bronwyn King, CEO, Tobacco Free Portfolios and an Australian Radiation Oncologist, gave a powerful keynote speech articulating the story of her pioneering work on tobacco free finance. Having worked for 10 years with patients suffering from lung cancer, she was distraught to find out that some of her pension fund was invested in tobacco, responsible for the annual deaths of seven million people, and began campaigning to encourage financial institutions to divest from tobacco stocks. Now AUD \$1.3 trillion dollars in Australian superannuation funds have been made tobacco free, and other countries around the world are also following suit, boosted by King's recently launched Tobacco Free Finance Pledge during UNGA week in September 2018. These initiatives, combined with governments introducing regulatory measures such as plain packaging and smoking bans, and supranational initiatives such as the UN Framework Convention on Tobacco Control (FCTC), are slowly helping us move towards a tobacco free world. And indeed, King asserted, to achieve 13 of the 17



SDGs requires a major shake-up of the tobacco industry: bold leaders need to stand up and press for change, she challenged.

### Social impact investment

There is a growing awareness of corporate social responsibility in the private sector and companies are finding solutions to align the interests of shareholders with more ethical investment portfolios. In addition to this, social impact investment is on the rise, with entrepreneurs and businesses in this area seeking to address social or environmental challenges through innovative business models that generate tangible and measurable societal benefits coupled with sound economics, with company directors accountable for achieving the goals. To pursue a societal shift in this direction, Filippo Addarii, Founder and Co-Managing Director, PlusValue, emphasised that we must engineer changes to an educational system that embodies fundamental social values and equips people with the knowledge and tools to act socially in every facet of their lives – for example through introducing “social” business schools.

### Financial literacy of health professionals

Continuing this theme, the importance of increasing the financial literacy of actors in the health sector, so that they can effectively participate in economic negotiations and influence systemic economic decisions impacting the health domain, was also recognised in this plenary. There is a need for

collaborations between ministries (e.g. economic and finance ministries with ministries of health) and institutions (e.g. WHO with the World Bank) as well as with the financial sector to create tailored policies and stimulate synergies. Health is entering a new economic paradigm and this needs to be recognised, said Ilona Kickbusch, Director of the Global Health Centre, Graduate Institute for International and Development Studies, Geneva, who asserted a need for health actors to pro-actively enter finance negotiations to tackle the challenge of NCDs and suggested that the WHO should have a Chief Economist who can actively engage in and shape financial discussions. She implored conference delegates to pay as much attention to the Financial Times as they do to health journals such as The Lancet, and suggested a new role for health diplomacy negotiation training related to financial issues. This approach of reaching outside the sector is something that those working on the commercial determinants of health can learn from work led by Michael Marmot and others on the social determinants of health, Kickbusch stressed.

### Partnerships for a fair profit?

Questioned by Martin McKee on why big business is moving into health, especially in some of the world’s poorest countries, Jan Kimpen, President, COCIR and Chief Medical Officer, Philips, explained how companies in the medical technology (medtech) industry are committed to addressing



unmet needs through vehicles such as PPPs. He agreed that there was a desire to balance shareholder value with stakeholder value – but in a way that breeds integrity. For example, he referenced Bronwyn King’s lung cancer patients and suggested that perhaps 20% of them could have been saved if their tumours had been identified and treated faster. It is also the responsibility of the medtech industry to design low-dose CT scanners to ensure patients receive the lowest dose of radiation possible. So, collaboration between different players in the field is enabling partnerships which save lives, he argued. Filippo Addarii suggested that we need to talk about assigning a moral value when it comes to finance. A fair profit – that is not beyond what it should be – so that investors receive their capital back and a small profit. The importance of partnerships in the social impact investment field is also key, Addarii emphasised, choosing projects and evaluating and measuring their achievement cannot be left to the financiers at the risk of purely focusing on easily achievable projects. Multi-stakeholder partnerships are key to identifying projects and goals and measuring their impact. Ilona Kickbusch cautioned that we need to be aware, however, that not everything can be tackled by partnership working – tobacco is a case in point where engagement with the industry is futile, for example. “WHO’s best buys on NCDs require government action which many industries will dislike”, cautioned Kickbusch.

### Health in all politics

The health sector speaks a lot of languages but it is still not sufficiently able to voice the language of politics. Too often, health specialists cannot effectively compete with policymakers from other sectors to bring public health needs to the top of the political agenda. Health is multidimensional and cross-cutting - the SDGs reveal how interrelated it is with other policy areas. The value of formulating other policies with a health and social lens therefore cannot be overstated. John Ryan Director, Public health, country knowledge, crisis management, DG SANTE, EC, pointed out however that all too often we are preaching to the converted, having insular conversations within the health sector. We need to branch out more and open these conversations to other sectors, as well as being prepared to bring health to the table by participating in topical discussions generated by other sectors. The health sector needs to think outside the box and be aware of where resources are and how to use them. Hence, the health debate should be shaped along two main interconnected axes: health as a purely biomedical topic and health as a social phenomenon,

thus including it within broader reflections on social justice. Therefore, it is necessary to act on the social and commercial determinants of health through policies that are able to reduce the inequitable distribution of socio-economic resources.

### EHFG and EIT Health Hackathon

The Closing Plenary also featured the prize-giving ceremony for the EHFG’s first ever Hackathon, jointly organised with EIT Health. 35 participants from 18 European countries were divided into seven teams and given 36 hours to develop innovative solutions to the problem of alcohol misuse in the young population. Three shortlisted projects competing for a jury prize and an audience prize were showcased in the Closing Plenary: GoBot, Alco-Drops and S.P.I.R.I.T. GoBot won the jury prize with their chatbot solution to support young people on nights out and make sure that everybody gets home safely. The app relies on three pillars that make it attractive for the young population (15-29): connecting young people in a short-term social network, keeping an eye on the user, and incentivising responsible behaviours with in-app discounts. The winner of the audience prize was Alco-Drops. Its inventors described it as “an innovative educational experience which provides a simulated story with multiple real-life scenarios showing the dangers of alcohol misuse.” They planned to provide the experience to pupils aged 11-16 in a classroom-based setting using virtual reality glasses, an omni-dimensional treadmill and a smart suit, to stimulate all senses (barring taste) virtual reality technology.

### Changing the status quo

Clemens Auer closed the session by asking delegates to take the good spirit, energy and ideas from the last three days home with them and be productive in making changes to further health and well-being in Europe. The Closing Plenary exemplified that if we think differently, we can press for changes to the status quo, and was an inspiring note on which to end the EHFG 2018.

Written by Erica Visintin, Maj Stougaard and Louise Boyle

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Track I  
Innovation for All







## Personalised Medicine & Health Literacy New Technologies, New Questions, New Skills

Organised by the Health Literacy Coalition; Sponsored by MSD

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

New technologies, such as personalised medicine, require new skills which are closely linked to the concept of health literacy. This also sparks debates on many social, scientific and ethical issues. When it is increasingly possible to “manage” health issues, questions arise amongst others about accountability, responsibility and the skills required. Is personalised medicine the future, or are we missing the basics required for its success? The workshop discussed how personalised medicine could change treatments and decision-making and what role health literacy plays in these developments.

Kristine Sorensen, President, International Health Literacy Association, moderated the session and began by asking the audience a few questions via Wisemply, such as whether they would consider taking an online DNA test (50% responded yes, 50% no) and whether they would like to know today if they were at increased risk of developing Alzheimer’s disease (69% responded yes, 31% no). Sorensen also defined at the outset a few of the concepts that were going to be discussed in the session.

### Health literacy...

...is closely linked to literacy and encompasses knowledge, motivation and competencies to access, understand,

appraise and apply information to form judgements and make decisions concerning healthcare, disease prevention and health promotion in everyday life with the aim of maintaining and promoting quality of life during the life course, supported by professionals and systems.

### Personalised medicine...

...is an emerging practice of medicine that uses an individual’s genetic profile to guide decisions made regarding the prevention, diagnosis and treatment of disease. Knowledge of a patient’s genetic profile can help doctors select the proper medication or therapy and administer it using the proper dose or regime.

### Personalised medicine requires patient awareness

Hollywood actress Angelina Jolie publicly announced in 2013 that genetic testing revealed she was at very high risk of getting breast cancer. Following Jolie’s preventive mastectomy, the number of women in the UK being referred to preventive genetic testing of BRCA1 and BRCA2, the human genes producing tumour suppressor proteins, almost doubled - a phenomenon that became known as the ‘Angelina effect’. The ‘Angelina effect’ provides an

example of the close relationship between personalised medicine and patients' awareness and levels of health literacy.

### **The ebay for health data and its opportunities**

Daniela Gunz, Director of research partnerships, healthbank, introduced the healthbank, a Swiss cooperative exchange platform for health data that is a neutral data storage centre for different kinds of patient data. According to the concept of the healthbank, patients always own and have control over their data and therefore can decide themselves about the degree to which they share their data with others. By collecting all kinds of data and giving patients the chance of sharing it with e.g. research bodies, healthbank aims to improve the quality of healthcare, paving the way for more targeted therapies and precision medicine. Thereby, it may provide the opportunity to achieve a shift "from a selfish silo approach to a collaborative open source approach", as Mark Lawler, Chair in Translational Cancer Genomics, Queen's University Belfast, put it. Genomic data could be shared not only among healthcare scientists in one country, but even across countries. However, the question remains if patients are literate enough to understand what their data tells them and who owns their data.

### **What role does health literacy play?**

Evidence suggests that between one fifth and one third of patients (depending on the country) show limited health literacy. This means that a considerable proportion of every country's population is facing troubles in accessing, understanding, appraising and applying health information. Personalised medicine would add another layer of complexity to an already very complicated field. One key to overcoming this problem is communication, explained Peter Nowak, Head of the Department of Health and Society, Austrian Public Health Institute. Good communication is always at the core of providing high-quality healthcare. In this regard, two main questions need to be answered: does the physician understand the patient and his or her health problems; and does the patient understand the physician's solutions to his or her problems? When both answers are positive, communication contributes to improved health outcomes. Also, it is a prerequisite for and central element of personalised medicine. However, due to the current set-up and attributes of (public) health systems - with e.g. missing or wrong incentives and financial constraints, communication increasingly loses importance across the entire treatment process. Examples were given of how nowadays, some

patients even pay for private physicians because they feel these doctors communicate better with them. This leads to health inequalities and healthcare systems are being split into two classes - an alarming development, not least as communication plays a key role in improving health literacy.

### **Personalised medicine introduces new challenges and ethical dilemmas**

The developments in the field of personalised medicine are related to several challenges, explained Katie Gallagher, Policy Advisor, European Patients' Forum. Firstly, personalised medicine increases the complexity of the medical field for patients, potentially requiring them to understand concepts such as their genetic risk profile, engage more actively in medical decision-making processes and share their health data. However, to date many HCPs are insufficiently trained in genetics to use personalised medicine strategies in their day to day medical practice - for example to explain treatment implications to patients. The general lack of access to reliable, easy to understand information concerning personalised medicine might also reinforce existing health inequalities, so it is therefore crucial to direct communications about personalised medicine towards all population groups, and not solely towards those who are most health literate. A second aspect relates to the fact that genetic testing risks opening a "Pandora's Box" and as a result may increase uncertainties for the patient. This needs to be handled with care, and the introduction of genetic counselling services are highly advisable here. Thus, knowledge created through the channels of personalised medicine is not only a responsibility; depending on the content it can also be a burden. Therefore, the right of patients also not to know about their risks was highlighted during the discussions.

### **A better-informed patient is a better-equipped patient**

The collaborative engagement of stakeholders is necessary to design health systems in a way that enhances shared decision-making between patients and healthcare professionals. Future coordinated action is necessary in the field of professional education and training to increase the level of patients' health literacy, which in turn is a prerequisite and the foundation for any further developments in the area of personalised medicine.

Written by Julia Bobek and Wiebke Seemann



## How good are our medicines?

### An operational agenda for EU & national policymakers

Organised by Open Society Foundations (OSF),

The European Alliance for Responsible R&D and Affordable Medicines (European Alliance),

The European Public Health Alliance (EPHA)



OPEN SOCIETY  
FOUNDATIONS



European Alliance for  
Responsible R&D and Affordable Medicines

At a time when payers are struggling to reimburse high-priced medicines, it is no wonder that a question like this should have sparked a lively debate in the peaceful valley of Gastein. And after all, as publicly announced by the organisers, that was exactly the purpose of the session. Already in 2017, the session organised by the European Public Health Alliance (EPHA) and the Open Society Foundations (OSF) was one of the most controversial of the whole Forum. This year's session on access to medicines followed in its footsteps. Two consecutive panels shed light on matters such as the evidentiary requirements for the approval of new medicines, and possible opportunities, challenges and tools for changing the current system.

#### Panel 1 – Assessing the Quality of Innovation

The first speaker to take the floor was Wolf-Dieter Ludwig, Chairman of the Drug Commission, German Medical Association and member of the European Medicines Agency (EMA) management board. He acknowledged that too few of the newly available drugs bring meaningful improvements

to patients. Even worse, many drugs are approved with only limited evidence, for example in instances where single pivotal trials or surrogate endpoints for progression free survival (PFS) are used. Ludwig argued that therefore, current “regulatory rules to approve medicines need to be reviewed”. Ameet Sarpatwari, Instructor in Medicine at Harvard Medical School, supported this line of thought and pointed to a recently published systematic review on ‘Evaluating Progression-Free Survival as a Surrogate Outcome for Health-Related Quality of Life in Oncology’. The authors of this study failed to find a significant association between PFS and health-related quality of life (HRQoL) in cancer clinical trials. Therefore, to ensure that patients are truly obtaining important benefit from cancer therapies, clinical trial investigators should measure HRQoL directly and accurately, ensuring adequate duration and follow-up. Natasha Azzopardi-Muscat, President of the European Public Health Association (EUPHA), took a more pragmatic stance. She questioned whether the current paradigm based on quality, safety and efficacy is still fit for purpose and called for the public good perspective to be considered. In her view,



the current EU proposal on Health Technology Assessment can contribute to improving the situation, but governments need to tackle the problem upstream. Bart Vermeulen, Deputy Director of Healthcare at the Office of the Minister of Social Affairs and Public Health, Belgium, agreed and gave credit to the BeNeLuxA collaboration, in which four EU Member States, including Belgium, are jointly negotiating drug prices. However, even with improved price-setting processes, the question of appropriate evidentiary requirements remains key. In the room, there was a general agreement on the need to change the rules of the game - especially with regard to the regulatory system. Furthermore, both the panellists and the audience acknowledged that the currently dominant narrative surrounding access to medical innovation and pricing should shift away from accusations and mutual recriminations, and rather focus on designing new and better rules for the sake of healthcare systems and ultimately for patients.

## Panel 2 – Case Studies & Tools for Change

After a short coffee break, a new set of panellists took their seats. First, three different civil society organisations were invited to illustrate concrete cases where the current regulatory system was circumvented, or not working as it should. Caroline Izambert Citizen Advocacy and Campaigns Coordinator, AIDES, France introduced the first example, elaborating on the Truvada case. Truvada is a combination drug produced by Gilead and is one of the most commonly prescribed medications for people living with HIV/AIDS. It is also the only combination drug approved in Europe for prevention (Pre-Exposure Prophylaxis - PrEP) amongst HIV-negative people. Izambert explained that in theory, all the patents on Truvada expired on July 2017. Yet, Gilead continued to hold the monopoly on the drug in several European countries via a Supplementary Protection Certificate (SPC), a legal tool which enabled the company to extend its patent on the medicine. AIDES supported the court case against Gilead in France and then at the European Court of Justice: both came to the conclusion that the patent extension was neither valid nor justified and ruled it illegal.

The second example was given by Luisa Crisigiovanni, Secretary General, Altroconsumo. The organisation made the headlines in 2017 when, after two years of legal battle, it won a court case against Aspen Pharma. Crisigiovanni explained that, supported by consumers and their reports, her organisation could prove how Aspen Pharma had withdrawn

four life-saving medicines from the Italian market. This move aimed to force the Italian government to agree to a very high price for the drugs in question. This case is a prime example of how a manufacturer can exploit its negotiating power by withholding vital drugs from patients to force exaggerated pricing. Crisigiovanni called on public authorities and governments to better engage with consumer groups and other civil society organisations, as their independence and their direct links with citizens can be crucial for spotting and denouncing irregular and illegal behaviour from companies around Europe.

Similarly, Vanessa Lopez, Executive Director, Salud por Derecho, Spain, highlighted how a stronger collaboration between NGOs across Europe is essential for spreading good practices that can help governments strengthen their negotiating position vis-à-vis manufacturers. Her organisation is on the front line in the access to medicines debate in Spain, where it is calling for the implementation of transparency rules obliging the government to release price-agreements. Adrian van den Hoven, Director General, Medicines for Europe, the European association for generic medicines and biosimilars, congratulated the organisations on their work and took the opportunity to advocate for a more balanced EU patent system. He elaborated further on the SPC legislation: SPC currently prevents European companies from even producing generics for protected medicines for export to countries without SPC for the drug in question. This also means that the drugs have to be manufactured outside Europe for them to be available on day one of the SPC expiration, van den Hoven explained. According to him, a review of the current system would benefit both the generics industry and European governments, as it would speed up the generics' entry into the market and therefore lower drug prices quicker.

The debate in Bad Hofgastein put an emphasis on finding concrete solutions for policymakers to improve access to medicines upstream. The choice is now in their hands: let us see where things stand one year from now.

Written by Francesca Cattarin

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## The future is now AI as a driver of sustainable healthcare?

Co-organised by COCIR and EHFG



The latest revolution in healthcare is amongst us: the very same Artificial Intelligence (AI) that already silently powers repetitive everyday tasks in other areas of life and work is now increasingly found also in healthcare. This EHFG 2018 session brought forward the visions and concerns of different stakeholders currently involved in this important transition.

### AI - opportunities and challenges. What lies ahead?

AI is an area of growing significance, offering numerous opportunities - but also posing many challenges. With longer life expectancy resulting in an increasing demand for healthcare and a health workforce that is not developing proportionally to this demand, we need supporting technologies. AI can contribute to addressing workforce shortages and other problems, e.g. by providing faster and more accurate diagnosis, supporting clinical decision-making, allowing for more precise treatments and enhancing clinical

trials. The field of radiology provides an interesting case study that exemplifies how AI could fill a gap: The increasing demand for image interpretation of about 10-12% per year is incompatible with the only slowly growing workforce (about 3% per year) (COCIR, 2018). AI could be used to help flag anomalies in medical imaging and support the radiologist throughout the diagnostic investigation. Among the most important preconditions for the successful integration of AI are trust, accessible data and sound regulatory frameworks. Furthermore, the costs associated with its adoption may be substantial, and therefore an additional challenge.

### The ball is rolling - status reports from the different stakeholders

Ceri Thompson, Head of the Policy Sector, eHealth, Wellbeing and Ageing Unit, DG CONNECT, started off by introducing the recent European Commission (EC) Communications

on AI for Europe and on the digital transformation of health and care. With the goal of strengthening research and innovation as well as making data more available, the EC is planning to invest heavily in AI - 20 billion euros by 2020. The second publication, on the digital transformation of health and care in the Digital Single Market, reviews many aspects of data and digitalisation: citizens' access to data, digital tools for patient empowerment and person-centered care, as well as better data for research, disease prevention and personalised health and care. The EC is taking a horizontal approach and looking for AI projects and initiatives that can advance development in the areas mentioned above.

The World Health Organization (WHO) follows a more policy-oriented approach to AI, with three consecutive events taking place already earlier this year: The World Health Assembly (WHA) Resolution on Digital Health, the launch of an initiative to address the future of the digitalization of health systems in the WHO European Region and the WHO-ITU Focus Group on Artificial Intelligence for Health. Liisa-Maria Voipio-Pulkki, Head of the Management Support Unit, Ministry of Social Affairs and Health, Finland and Riina Sikut, Minister of Health

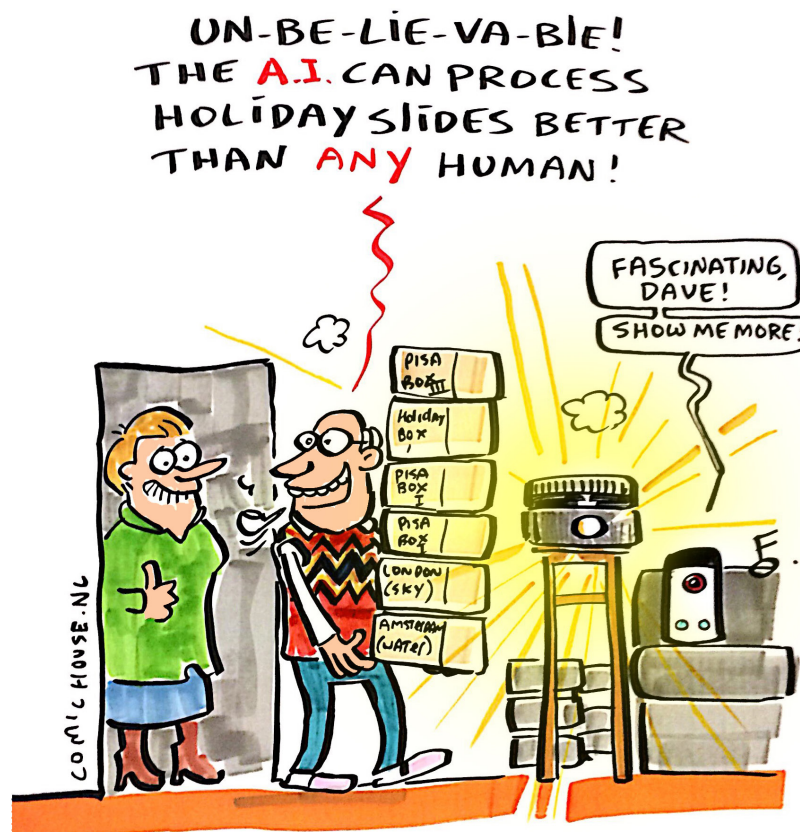
and Labour, Estonia, outlined how their governments are respectively working on reducing fragmentation and improving data quality to support the development of AI solutions.

### A Practical Perspective - how is AI bringing real-time change in healthcare?

The question was raised of how to increase public awareness about the potential of technology and of how patients may best benefit from this potential. Here, a use case of CT-based chest imaging was presented, where AI is designed to find and visualise both smaller and larger vessels. It can thereby provide volume-based calculations of lung disorders such as emphysema and detect lung cancer nodules.

One particular difficulty discussed during the session were the different concepts hiding behind the term "AI". For example, is it meant to refer to augmented or to artificial intelligence? The different approaches to understanding and conceptualising AI is considered a challenge also by the WHO and was therefore one of the first questions the WHO-ITU-focus group addressed.

### Trust, transparency and regulations



Several industry representatives emphasised that trust needs to be earned - and is very difficult to reestablish once lost. Trust is closely related to the transparency of the systems and algorithms behind a conclusion or recommendation. One possible approach towards setting up a trustworthy regulatory framework for AI would e.g. be to consider AI-systems as 'medical device software'. Also, Emma Woodward, Chief Operations Officer, European Oncology Nursing Society (EONS), pointed out that machines cannot substitute the care provided by a human being, but that AI can support nurses in their clinical work. She explained that cancer patients are open to new technology - if it can provide faster and more accurate diagnosis.

Talking about the necessary frameworks for developing and implementing AI, another important question was raised by the audience: "Who should take the lead?" Clayton Hamilton, WHO Regional Office for Europe, pointed out that AI can potentially be regulated in great detail. He suggested there may be the need for an independent body that can evaluate its clinical impact.

### Data quality and data availability - Who owns the data?

Broad questions on both ethics and regulations were raised throughout the session: Who is responsible when something goes wrong and an AI technology causes harm? The user or the software developer? The healthcare organisation offering the service? Is someone directly accountable, or would an insurance system be feasible, that compensates for this kind of errors - so that we can learn from them? Can we apply a traditional approach to ethics? How will we define medical errors in the future?

Specifically the issue of ethical decision-making was discussed: Even though a machine may be capable of making decisions, there is still the question of whether it would be able to distinguish between the most effective and the most ethical option. Humans clearly play the crucial role in deciding whether and where AI is implemented, and what its intended function is in a specific context. We need big amounts of high-quality data in order to use AI, and the data digitalisation will continue to gain importance. Availability of and access to data are major challenges, and so is winning and keeping the trust of citizens with this regard - especially against the backdrop of increasing concerns about data usage and privacy.

Patient empowerment was another important aspect addressed by both panelists and audience. It was stated that when talking about empowerment, we are automatically talking about our willingness to prioritise patient needs. Lydia Makaroff, Director, European Cancer Patient Coalition, pointed to the right to non-participation in this context - despite the many potential benefits. One of these also includes supporting patients in their health management, e.g. by automatically capturing and processing information on symptoms, based on which patient and doctor can then be alerted about any changes in health status that may require action.

### Conclusions

Artificial Intelligence has the potential to contribute to providing innovative healthcare for all patients, a.o. by working towards sustainable systems where workforce gaps are being addressed. This can be achieved without compromising the evidence necessary for ensuring the safety of AI and its use. The different stakeholders gathered in the room shared a common goal: leaving no one behind in this AI-revolution. After all, AI is already present in our everyday lives. The question is not whether it will be implemented in healthcare, but rather how. When answering this question we must always bear in mind that in the end, it is the patients we have healthcare for.

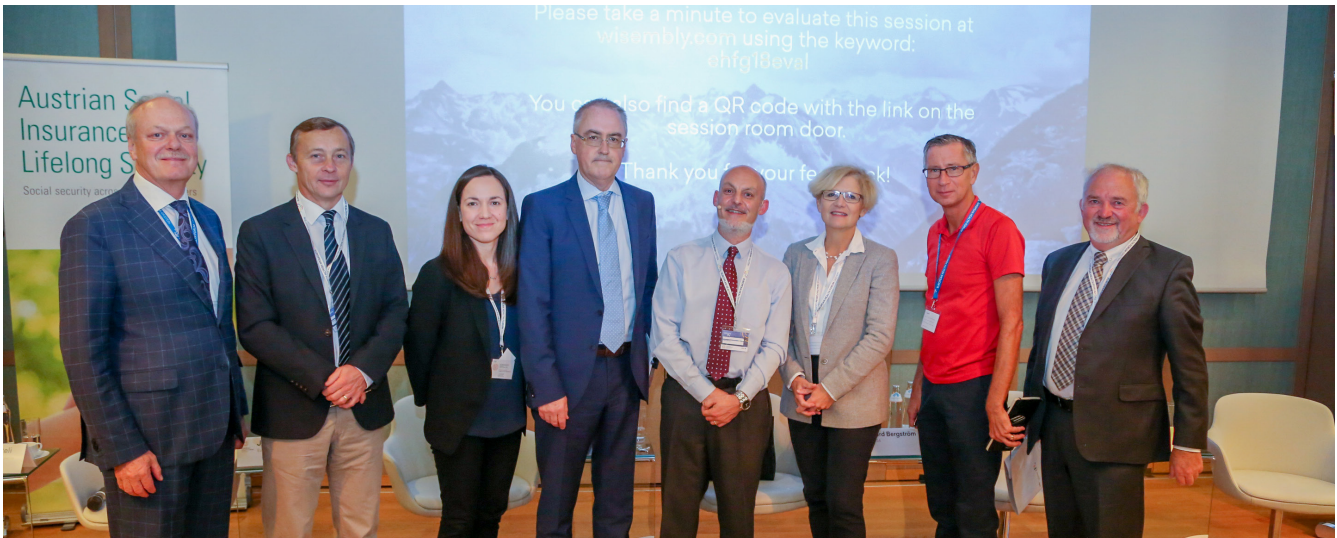
Written by Aleksander Skoyeneie, and Stefan Buttigieg

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## Innovative Medicines for the good of all

### New business models in research funding & cooperation

Organised by the Main Association of Austrian Social Security Institutions and National Institute of Health and Disability Insurance (NHDl), in cooperation with the European Social Insurance Platform (ESIP)



This forum session focused on research models within the pharmaceutical value chain, specifically discussing how new models for R&D could create better access to medicines in Europe. Amongst other aspects, potential changes in legal frameworks at both state and international level were addressed. How can we build and secure trustworthy and efficient healthcare systems?

#### The status quo of the current R&D system

Healthcare is a hybrid industry. It combines products, e.g. pharmaceuticals and medical technology, and services, like care delivery. Healthcare systems need innovation in both areas. At the same time, they are restricted by limited resources and need to contain costs. Which investment is a sensible one, what kind of research is promising and likely to yield the “right” kind of benefit? To date, healthcare systems are often the passive or even unwilling recipients of innovations they did not ask for and may not be able to afford. One area of medical innovation where this problem has taken centre stage in numerous discussions in recent years is drug development. During the conversation in this particular session, attention was called to how little internal capacity for R&D there is in our healthcare systems, and it was therefore suggested that there

should be joint ownership between different players. As yet, researchers, healthcare providers, patients and companies are poorly aligned, and participants in the session felt that the R&D process needs to be refocused, be it via gradual adjustment or through more radical reform. One aspect mentioned in this context was that research priorities need to be multilaterally defined already early on, and need to be clearly communicated. In general, a concerted effort that spans the whole of the innovation process is required, beginning with the promotion of efficiency in evidence generation and ensuring that only relevant information is considered. A particular challenge brought up in this regard was data sharing and capturing real-world evidence; the interoperability of e.g. electronic health records was considered less problematic. In terms of the research process, a stronger focus on transparency was suggested, especially in relation to how funds are awarded and used. In essence, there was a strong feeling in the room that rather than the current fragmented, pipeline-oriented approach, the earlier involvement of different stakeholders was crucial to ensure targeted R&D that yields affordable drugs.

#### The way forward

To point to alternative ways of organising research agendas



and funding, two initiatives were presented. The first, Horizon Europe, is the new EU research programme scheduled to kick off in 2021. For it to work optimally, it is crucial that MS contribute and acknowledge the need to invest in equipping their healthcare and social welfare systems with the best solutions possible. It was highlighted that for the successful implementation of innovation, Member States need to be involved at a very early stage even in the design of research programmes. And there is support at the EU level: DG SANTE can help create and guide incentives for innovation e.g. in the field of pharmaceuticals, like it has already done in paediatric and orphan drugs legislation. It is crucial to generate more mechanisms like this to better integrate the needs of healthcare systems into research agendas.

The second funding opportunity that was introduced was the Multiannual Financial Framework (MFF) - European Social Fund Plus (ESF+). The framework will include a specified amount dedicated to the health sector, to support health promotion and disease prevention. Despite these and other efforts, even the joint investment from the EC and MS is ten times lower than the investment of the top 20 pharmaceutical companies. The recently published WHO report on Priority Medicines includes a whole chapter on promoting innovation. It presents learnings from the Innovative Medicines Initiative (IMI), looking at innovation in the regulatory system, new pricing and reimbursement models, real world data, and the value of public health based R&D models. One of its key messages is that meaningful innovation needs to incorporate the patient's perspective, e.g. by involving patients in the prioritisation process and including patient-defined and reported outcome measures. Within IMI, there is a clear patient engagement strategy. Its two flagship projects are EUPATI, with a focus on patient education, and PARADIGM, focussing on patient engagement across the different stages of medicines development. This includes the design of clinical trials as well as early dialogue on evidence requirements with regulatory bodies, HTA agencies and the industry. Among the factors identified as crucial for successful public private partnerships (PPPs) are transparency, a sound ethical framework, trust (co-creation and collaboration) and sustainability. The European Patients' Forum (EPF) has already published a framework for the value and pricing of medicines, outlining how to ensure there is a fair return on investment for public financing. With all this in mind, it is important to recall that innovation is also needed in areas besides pharmaceuticals. Kieran Walshe,

Professor of Health Policy and Management, Manchester Business School, pointed out that while a large amount of research has been done regarding Alzheimer's disease and billions of euros have been invested in drug development and distribution, there is less research on prevention and on how to improve the quality of life for people with Alzheimer's disease. Managing health insurance budgets is a key concern for every MS, and it is particularly challenging when considering all the different kinds of needs a health system has to cater for. Marjan Sušelj, General Director, Health Insurance Group of Slovenia, also raised the topic of diagnostics. For example diagnostic devices are currently reimbursed below the value they bring to treatment. However, there are already discussions about making diagnostics part of the next IMI - for a better alignment with actual societal needs. Again, the importance of the improved inclusion and collaboration of MS was highlighted, especially via their finance ministries: to ensure efficient public investment, regulators, payers, healthcare providers and other stakeholders need to sit down at the same table.

### How can we improve the public aspect of PPPs and similar initiatives?

Any new PPP on health innovation needs a strong focus on the SDGs, including sustainable healthcare systems. Healthcare actors and service organisers, including payers, play a vital role in any such partnership and in setting research priorities. We must remember that healthcare innovation is much broader than medicines alone and includes diagnostics, medical technology, health services and healthcare organisations. We need a multiphased approach; rather than blaming misguided and poorly aligned research on the pharmaceutical industry, the aim needs to be to get all stakeholders on board and make research more affordable. Greater scrutiny of investment in healthcare research is required, and key to this is the use of EU funds in a collaborative way, with leadership at both international and MS level. Furthermore, other sectors should be part of a new IMI, to facilitate a better alignment with current and future societal needs. Most importantly, to make new partnership models work, the early public engagement of citizen and patients is required to anticipate and solve public trust issues.

Written by Oana Motea, Franjo Caic

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## Improving cancer care

### Perspectives on value & access from the cancer care community

Organised by the European CanCer Organisation (ECCO), the European Federation of Pharmaceutical Industries & Associations (EFPIA) and the European Cancer Patients Coalition (ECPC)



As the European population ages, the burden of disease attributed to cancer is increasing - and with it the demand and quality expectations for cancer care. The advent of new and expensive therapeutic options makes understanding their respective value fundamental to the optimisation and sustainability of future cancer healthcare budgets. In this context, value is typically defined as the ratio between patient benefit and cost. It takes centre stage in all healthcare budget discussions, with clear implications also for cancer care financing and access to medicines.

There are numerous questions that need to be addressed when engaging in this kind of assessment: what matters most to patients? How can we ensure that patient preferences are reflected in policy? How can oncology data help determine value across the cancer care continuum? In this forum,

organised by the European CanCer Organisation (ECCO), the European Federation of Pharmaceutical Industries and Associations (EFPIA) and the European Cancer Patients Coalition (ECPC), these and other issues were discussed. In particular, some recent initiatives in the field were highlighted, including a multi-stakeholder discussion paper on “Taking action on cancer together: delivering the future of cancer medicines in Europe”, several ECCO projects on value-based healthcare, and the latest EFPIA report on the European oncology data landscape.

#### Harnessing patient viewpoints to assess value in cancer care

Tamsin Rose, Senior Fellow, Friends of Europe, set the scene for the ensuing discussion by referring to what had already been stressed earlier in one of the EHFG 2018 plenary sessions: in



the future, we will live longer, but in poorer health. Healthcare, and particularly cancer care, may therefore be described as a “black hole” for resources – if we fail to evaluate relevant outcomes. Value determination and a multi-stakeholder approach are key to resolving the issues at hand. Yolande Lievens, Project Chair, ECCO, pointed out that one of the barriers to value-based healthcare is fragmentation and that therefore, a united voice is needed to nudge policymakers towards a new approach. Though wider awareness of the potential of value assessment in healthcare has not yet been achieved, the topic is increasingly permeating the agendas of scientific meetings and discussions amongst healthcare professionals. Lydia Makaroff, Director, ECPC, highlighted how the patient perspective is fundamental to making progress: the patient’s point of view is a prerequisite for value assessment and can be included e.g. through quality of life measures as secondary endpoints in all cancer-related clinical trials. With healthcare still being organised in silos rather than around patient pathways, patient organisations could play an important role in the reorganisation of cancer care around new, value-centered models.

Alexander Roediger, Chair, EFPIA Oncology Platform, then talked about a question on which the pharmaceutical industry is frequently approached, namely how value will be incorporated into drug development. He explained that future pharmaceutical industry business models will focus

on reaching out to stakeholders from different fields to identify priorities for and barriers to access to medicines. The aforementioned EFPIA report on access to medicines is the fruit of such interdisciplinary engagement. It was published after a pan-European discussion on cancer involving 150 cancer experts, including patient organisations, clinicians and policymakers. The report highlights the variability in cancer spending across Europe, with an up to six-fold higher spending in some countries compared with others. Furthermore, the uptake of new medicines is still slow, with delays ranging from five months in the Netherlands to up to four years in Portugal.

The panel discussion continued with Ken Mastris, Board Member, ECPC, stating that patients want to be involved in decision-making. He reaffirmed that innovation in cancer care should aim to be patient-centred, to improve existing care and, consequently, to improve patient quality of life. The barriers identified by patients to achieving these objectives are manifold and include low health expenditure on cancer, the lack of dialogue between patients and health professionals, and limited patient involvement in decision-making. In order to improve access to innovative medicines, patient organisations suggest that clinical trials are made accessible to patients, fast track approvals are made more transparent with clear criteria, and patients are included in health technology assessments as well as drug research and development.





The floor was then opened to questions from the audience. The complexity of the topic and of the prerequisites for making value-based cancer care a reality were reflected in the multitude of audience questions and remarks. These ranged from how training for healthcare professionals was still fostering a “lone cowboy” mentality without recognising interdisciplinary engagement and the patient as part of the process, to how value is hard to objectively define and susceptible to geographical and cultural variation. Further points were the failure to address quality of death, the need for the increased participation and autonomy of specialised nurses, and the apparent lack of political courage that may hinder change.

### The oncology data mosaic and action towards its optimisation

The second part of this forum was kick-started by Vincent Clay, Senior Manager, EU Government Affairs, Pfizer, presenting the collaborative paper “Data as foundation for value and access: the oncology data landscape in Europe”. This multi-stakeholder report describes the current state of oncology data in Europe and how it is already improving the quality and affordability of cancer care. It also identifies five main barriers to the optimal use of oncology data: political (conflict between European and national-level health strategies and approaches); economic (patchy and fragmented funding, contrasting commercial incentives and interests, lack of required human capital and capabilities); societal (disparate public, patient and healthcare professionals’ mind-sets, with a particular focus on data protection concerns); technical (cancer complexity, infrastructural challenges, the need for defining data and standards; data processing and linkage requirements, and quality and consistency demands) and legal (data ownership, consent, governance, access, privacy and security). The report further suggests 28 macro-level actions to overcome these barriers and improve the current European healthcare data platform. Some of these strategic solutions have been prioritised, since they are specific to oncology. They focus on awareness building measures like the launch of an oncology data summit, the development of standards like quality accreditation frameworks, and infrastructural enhancement, e.g. by establishing a comprehensive real-world data source. Improvements like these are all aimed at enabling innovative value-based pricing models in cancer healthcare.

In this context, Lievens emphasised once more how only a

multidisciplinary environment can make comprehensive and useful European oncology data a reality across the whole cancer continuum, including prevention, screening, diagnosis, and curative and palliative treatment. She introduced ECCO’s Value-Based Healthcare Project, which gathers insights from multiple stakeholders to help improve access to innovation. The report contains three calls for action: developing value methodologies for loco-regional cancer treatment, obtaining a wider consensus on endpoints and patient-relevant outcomes, and using a blended approach to evidence generation, which includes real-life data in addition to the data obtained from experimental and non-experimental studies.

This EHFG 2018 session highlighted the challenges related to any attempt to define value in healthcare. We must acknowledge how perceptions of value are determined by a multitude of factors such as type and stage of disease, and that they are, ultimately, individual. There was a consensus in the room that change is inevitable for cancer care, and there was optimism that cooperation and multi-stakeholder engagement are already happening now, working towards optimising the patient’s journey both for the individual and society as a whole.

Written by José Luis Sandoval

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## Blockchain for Dummies

Organised by European Health Forum Gastein



With the recent worldwide hype around Bitcoin and other cryptocurrencies, there is a surging interest around blockchain technology, and many players from different fields are trying to identify how to best use it in their field of business. However, it is important to state that Bitcoin and blockchain are not the same – while blockchain provides the means to record and store Bitcoin transactions, it has many uses beyond Bitcoin. This session was focused on clearing up misconceptions around the topic of blockchain and explore the advantages and limitations of its use in health care.

Setting the scene, moderator Richard Bergström, External Pharma Lead, SICPA SA, explained that with its role as a foundational building block, blockchain is not a panacea that could be universally applicable to every aspect of the healthcare system - but it can certainly provide solutions for many 'new' components of healthcare, such as electronic health records (EHR) or integrated care, engendering a previously unattainable level of trust. The latter is especially important considering relatively frequent data breaches, but also because of the new GDPR laws.

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### Why Blockchain?

Glen Ogden, General Manager, Guardtime Health, took on the rather difficult role of explaining the origin, structure and technical background of blockchain, as well as its wide use in different businesses. With an audience primarily from the health sector, it was important to adapt specialised IT vocabulary and clearly demonstrate to participants blockchain's advantages over different ways of managing data. Considering the challenges faced by the health sector around data, such as a lack of interoperability in the large and multi-stakeholder system that often reduces cost-efficiency and the lack of a single source of truth which could prove veracity and provenance of data or patient consent, health systems are in desperate need of a comprehensive solution.

### What is Blockchain?

Blockchain started in 1995, stemming from the idea of linked timestamping as a way of verifying the time and type of change in a ledger, and essentially consists of a connected chain of data records, where each new data block contains encrypted information about the previous block. This kind of



technology soon evolved into Bitcoin, a cryptocurrency that provides anonymous online money handling without any kind of higher financial authority. However, Bitcoin and blockchain are not the same: although blockchain provides technology to manage Bitcoin, it has many other uses, and different types of use are appropriate for different applications. For example, as data cannot “be forgotten” in blockchain without breaking the linked data structure of the chain, it is suitable for smart contracts but unsuitable for storing health data – however the blockchain itself is useful to track how data has changed over time and thus has potential to revolutionise the way in which health data can be shared and accessed securely. It is important to state that data is never published in blockchain – rather, the distributive ledger technology is used, and the only information provided and publishable is the timestamp. Using this system for tagging all electronic data provides signing time, signing entity and data integrity – these data points are proven and can be checked via the receipt which is published with any new changes to the ledger status of each entry. For the system to work properly, it must be set up without relying on a centralised authority. Service providers cannot play the role of auditors – rather, there must be independent audit oversight.

### The Estonian example

After being the victim of the first state-sponsored cyber-

attack, Estonia became the first almost entirely digitalised country in the world. Blockchain was implemented throughout government systems, providing transparency – both for governing bodies and for citizens –, data traceability, and data immutability, significantly increasing trust and introducing a new level of integrity. Although all actors had access to the centralised component of health records, and there was no need for blockchain facilitation of that specific matter, blockchain was introduced and used to prove the record that was being saved and used had integrity and could not be modified without leaving a trace, thus avoiding any kind of malpractice or multiplications of unnecessary checkups. Moreover, there was a new level of transparency provided to each individual, only made possible through the use of blockchain – any access to a citizen’s data is shown in blockchain, and the individual is informed about it.

As was further clarified by Ain Aaviksoo, CEO, Viteo Health and former Deputy Secretary General for E-services and Innovation at the Ministry of Social Affairs, Estonia, the two-layer system of data ownership and protection is key to country digitalisation. The first layer is the national government-controlled layer, and the second one is the audit layer, which controls the government. The trust that this system has built over the last ten years has facilitated agreements and projects like the gene-sequencing project mentioned by the Estonian





Minister of Health, Riina Sikkut, in the Opening Plenary. What is important to stress is that while not everyone understands the mechanisms behind blockchain technology in detail, the trust generated by its use has met with results.

### The UK example

The NHS is trialling a new technology to help GPs take care of patients with diabetes, cardiovascular diseases and arthritis. When a patient presents with one of these three diseases, the GP enrolls them in a system, uploading their medical records to an app, which then becomes a constant monitor of the patient's health status, as well as an advisor for the patient's pathway. The app informs the patient about their habits and necessary lifestyle changes and notifies the GP of missed appointments or sudden significant changes to the patient's state. There are two different types of data records: one that is generated by the app, and one that is added by the clinician. The two are clearly separated.

This type of treatment is not mandatory, and patient's consent can be withdrawn from the app at any point. With the blockchain receipt, the patient can access information about who is looking at their records.

This app can be further used for clinical trial patient acquisition, as it provides access to patients without the agency of already overworked GPs and provides much greater chance of enrolling the ideal type of patient on the trial. It is completely one-sided until the patient personally decides to opt-in to participation. Furthermore, to prevent drop-outs, there is a special concierge service that provides a physical person who checks on the patient regularly, while also being supervised by the concierge app. All of these are managed through blockchain tagging technology.

### Interoperability, investment and implementation

After explanation of the technology and its relevant uses, ample time was given for questions from the audience.

One audience member wondered how blockchain compares to 'older' technology that is still being used for patient records, i.e. chipcards. Ogden explained that while chipcards work on the technology of public key infrastructure (PKI), they are not interchangeable, or rather, PKI can and should work through blockchain. This way, the trust and security would be much higher: if the chip that is being used for a certain PKI gets compromised, every single chipcard in existence needs to be

replaced. However, if the PKI is connected to blockchain, only the cards that are directly affected need to be identified and replaced, and there is no danger of compromising the data.

Questions about costs of blockchain were welcomed with an answer about different uses of blockchain: in the case of health, no real data is being stored on or shared via the blockchain – merely access to and modification of existing data is tracked, which means that there is no need for additional big computing strength. The only cost then would be a good provider and manager of blockchain access, a company that takes care of it. In the case of Estonia, it has already been shown that the necessary technology pays for itself, and soon starts saving money – by now, there is a trend of 30% rise in savings.

A suggestion for starting with blockchain in a small country would be to start from simple, small issues, basically addressing data flow between stakeholders faced with a problem where there is a lack of trust.

Lastly, there was an enquiry about whether interoperability was a prerequisite for the functioning of blockchain. Ogden explained that while it would be ideal that interoperability be the basis of blockchain infrastructure, there is additional interoperability software for blockchain that basically supports the development of interoperability. Such software works on the premise that the data being transferred from one system to another has to change, and there needs to be a body that can prove its longitudinal existence regardless of its digital shape – which the interoperability software provides.

### Blockchain – what's next?

In conclusion, blockchain use is still relatively unknown and the awareness of its benefits is still not as commonplace as it should be. If healthcare players want to keep up with big data development trends and citizen collaboration, blockchain is the next logical move. Pharmaceutical companies have started cooperating, slowly introducing blockchain technology, so it is time for national health systems to start thinking about it as well.

Written by Matej Vinko and Julio Muñoz



## Enabling the digital transformation of cancer care in Europe

Organised by Bristol-Myers Squibb



Digital opportunities are redefining frontiers for patients, healthcare professionals and hospitals when it comes to securing the future of cancer care. They can facilitate an increase in patient-centred care, greater sustainability and better health outcomes, and open up new pathways for the discovery and development of treatments. This EHFG 2018 session discussed the digitalisation of health and its potential to create more efficient healthcare systems as well as concerns related to privacy and data accessibility.

### Improving digestive cancer outcomes with digital health

The survival rate for patients suffering from digestive cancers is overall poor, although it varies with the type and stage of cancer as well as the treatment received. Of the more than 800,000 people in Europe diagnosed every year, approximately 500,000 patients die. By using already available technologies, 125,000 lives could be saved every year, according to Stefan Gijssels, Executive Director, Digestive Cancers Europe and EuropaColon. Digital health can improve disease outcomes - but only if patients have quick access to it. One example of its application is when healthcare professionals digitally track patients' activity and health status, using the information obtained to work in conjunction with the patient towards improving adherence, optimising treatment in real time, or addressing more general lifestyle questions. Digital health can also connect patients for the exchange of ideas, experiences and mutual empowerment. "Now we have real time and real

life data to determine which practices need to be encouraged and which to be reduced or even stopped", said Gijssels.

Thomas Geuenich, CEO, Noona Healthcare, elaborated on Gijssels points and emphasised that digital technology can contribute considerably to shifting the focus from physician-reported to patient-reported outcomes. Through the improved generation and communication of new insights, health professionals can be enabled to provide better and more personalised care. In other words: new technologies are not designed to substitute, but to support and enhance the everyday work of nurses and physicians. Also in cancer care, this can both improve survival and save clinical resources. Furthermore, with improved analytics cancer clinics can better understand how well their patients are doing and how satisfied they are, and researchers and ultimately patients can benefit from increased access to real world data.

### Digitalisation as a driver for improved care and education

Marisa Co, Vice President R&D Business Insights & Analytics, Bristol-Myers Squibb (BMS), further elaborated on the points made by the previous speakers and agreed that digital health can accelerate clinical research and patient engagement, enhance productivity, and pave the way towards truly personalised healthcare. She introduced I-O Optimise, a pan-European initiative established by BMS that provides real-world insights in the evolving lung cancer landscape

by merging data from different sources across Europe. Co proposed that the EU leadership should further enable data accessibility and connectivity to improve research-quality data resources. She also pointed to the efficiency gains in cancer care that could be achieved with improved data use.

Shafi Ahmed, Professor and Colorectal Surgeon, The Royal London and St Barts Hospital and Director, Medical Realities, featured in a TEDX video clip broadcast during the session, in which he referred to the advantages of digitalisation in a slightly different context. He explained how as a surgeon he uses technology like Google glasses and virtual reality to stream operations live, thereby enhancing surgical education globally. He urged the health community to take action and find common ground, to forge ahead, test and apply diverse and creative new solutions. For as the science fiction author William Gibson said: "The future is already here – it's just not very evenly distributed".

### Fusing "digital" and "health"

Cecilia Bonefeld-Dahl, Director General, DIGITALEUROPE, explained the importance of bringing "digital" and "health" together: digitalisation is one of the most important drivers of growth and innovation, and can take matters from a local to a global level. She also emphasised that health services should be centred around the individual, and that through data, we are better able to understand an individual's needs and expectations. Bonefeld-Dahl referred to research that has shown that 80% of people are willing to share their health data, if there is a benefit. However, to make this happen and unlock the potential of digitalisation in health, understanding data and privacy is crucial. A common framework to develop safe and secure ways for using data in health and healthcare is needed.

### Evaluation of and adaptation to new technologies

Kostas Athanasakis, Health Economist, Research Fellow, NSPH Athens, raised the question of how to evaluate new technologies. How can we assess whether a given technology really adds value? How can we evaluate and compare alternatives? These are important questions to address for successful digital transformation in health. Mathias Ekman, Director Industry Solutions, Microsoft, emphasised that both users and policymakers need to prepare for and adapt to new technologies. One particular challenge in this regard is the sheer speed of technological developments, and making sure that they are sustainable and evenly distributed.

### Citizen empowerment and person-centred care

Related to this was also the input provided by Ceri Thompson, Head of Sector, eHealth and Ageing Policy, DG CNECT, EC. She highlighted the importance of giving EU citizens better access to their health data. Digital services can be used as a means to citizen empowerment and person-centred care. Although EU-level action on data pooling and expertise can lead to earlier diagnosis, people-centred services and better prevention, action is required by the individual actors in healthcare, too. To date, only 4% of hospitals exchange clinical care information about patients electronically with other care organisations in other EU countries. Furthermore, the potential annual savings in Europe resulting from the use of mobile health applications are estimated to be €69 billion Euro, but only 9% of hospitals in Europe allow citizens to access their patient records online, and most of them only concede partial access. The EC has now developed a digital data service for eHealth that aims to support EU MS in sharing patient summaries and prescription data.

### The impact of the digital revolution in health

Discussants of this EHFG 2018 session agreed that digital technologies have the potential to revolutionise cancer care and put the patient at the centre of the healthcare system. Linking clinical data from different sources - including information on diagnosis, treatment and patient-reported outcomes - can contribute to higher quality healthcare and lead to better health outcomes across Europe. Improved communication between patients and healthcare professionals has not only the potential to yield more efficient care, but also to empower patients and pave the way towards truly person-centred care. Digitising healthcare and adapting to new technologies should be considered a joint project between patient-representatives, governments and the private sector. The EC should continue to take a leadership role by enabling greater health data accessibility and connectivity across MS, supporting governments in the digital transformation and setting frameworks for future development and privacy measures.

Written by Gergő Baranyi and Vladana Stefanović

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## Man vs. Machine

### An Oxford Union style debate on Artificial Intelligence

Organised by acumen public affairs



This workshop explored the risks and rewards of the use of Artificial Intelligence (AI) in health: health systems and humans generate an enormous amount of data, which is now increasingly channelled toward public health - using AI. The growing AI health market is expected to reach a staggering \$6.6 billion USD by 2021, from just \$600 million USD in 2014. The use of AI, the actors controlling its use, and the ways in which AI can and will work are still uncertain. And this uncertainty has split people's opinions about whether the rewards of AI outweigh its risks.

The moderator of the session, David Rose, Director, LACS Training, set the scene and introduced the motion: 'AI in healthcare: the rewards outweigh the risks'. The workshop used an 'Oxford Union'-style debating format. The audience cast a pre-debate vote, and opinions were heterogenous in the multi-stakeholder audience, with 28 votes in favour of the motion and 11 against. During the debate, each side, one in favour of the motion and the other against, had ten minutes to present their arguments through a proposer and a seconder. After these initial arguments, the moderator took questions from the floor. Both sides were obliged to answer each question within two minutes. Following the Q&A, the two teams had five minutes to make concluding remarks before a final vote.

**Proposing the motion: 'AI in healthcare: the rewards outweigh the risks'**

Rachel Dunscombe, CIO, Salford Royal NHS Foundation Trust

highlighted the benefits resulting from the use of AI in healthcare that are already evident. At Salford Royal Hospital, her place of work, AI is being applied in the form of clinical decision support and triage tools. It is quantifiably saving lives and improving the quality of life of patients. Furthermore, through the automation of routine tasks AI can reduce the workload of HCPs, which also benefits patients. For example in ophthalmology clinics, where appointments are only about five minutes long, AI can enable the clinician to focus on the person seeking help rather than on routine questions.

Brian O'Connor, Chair, European Connected Health Alliance expanded on Dunscombe's line of thought by arguing that using AI in healthcare is like introducing a new technology: initially, it is met with resistance, but eventually - when implemented in a well thought out way - it becomes widespread. He compared the application of AI to crossing a road while a car is approaching: the car could kill you, but when being aware and careful, crossing safely is clearly possible. Accordingly, we need to be aware of the potential downsides of AI, but with careful design, use and regulation we can remove or mitigate any negative impact. Not using AI presents far greater risks to patients, he asserted.

**Opposing the motion: 'AI in healthcare: the rewards outweigh the risks'**

Martin McKee, Professor of European Public Health, London School of Hygiene and Tropical Medicine, began the argument against the



motion by suggesting the debate was restricted to highly complex AI. He argued that 'simple' approaches such as basic algorithms or regression models were not what people meant by AI. McKee defined complex AI as being effectively a black-box, where the methodology is so complex and changeable that it is impracticable to understand. What further contributes to the overall lack of clarity is the fact that many of these algorithms are developed by commercial companies and are therefore treated as trade secrets. Referring to the potential application of AI in e.g. cancer diagnosis or for suggesting treatment options, McKee argued that the danger here is that people might not get appropriate care because the 'computer says no'. He also put forward that even simpler AI is fraught with risk, pointing to evidence that mammograms already annotated by a computer reduced the accuracy of the diagnosis of the radiologist.

Tamsin Rose, Senior Fellow, Friends of Europe, then referred to one commonly known problem that is also very relevant in the context of AI: garbage in, garbage out. If the (big) data being used by AI are of poor quality or contain inaccurate information, AI will get things wrong, too. Big data tends to be unstructured and biased, which should in itself be enough to raise concerns, according to Rose. She also brought up the issue of security. What happens if someone hacks an algorithm used for AI? Also, there are unanswered questions about who is responsible if something goes wrong. Should AI be permitted to make the decision as to who lives and who dies?

### Floor discussion

The floor discussion covered a lot of different aspects, but many points related to commercial actors in AI development and the risk of malicious use. The responses to questions on these themes highlighted the difference between the two sides: those who felt that the rewards of AI outweighed the risks believed in the capacity

of partnerships, regulation and national governments to promote ethical behaviour and prevent misuse. Those who felt the risks outweighed the rewards did not. Another question that attracted heightened attention was who would be responsible for (wrong) decisions made by AI. Dunscombe argued that clear lines of responsibility are possible, for example by designating people who are in charge of certifying that a given AI routine is clinically safe. A practical issue with this proposition was introduced by McKee: recruiting programmers who can actually understand the algorithm may be near-impossible for public hospitals.

### Closing arguments

The proposing team concluded by claiming that we "have a duty of care to use AI. To fail to do so is to harm our patients." The opposing team remained unconvinced: "back to the motion - AI in healthcare, the rewards outweigh the risks. No 'might', no 'will'. As worded, the motion is not proven."

### Final vote

With a final vote of 28 for and 20 against the motion, opinion seemed to have shifted slightly against the motion. The audience had also grown during the debate. In the end all sides agreed that whilst AI can doubtless be a crucial tool for sustainable healthcare systems, we first need evidence of its benefit and awareness of its risks. Understanding these is critical to ensuring the rewards are worthwhile.

Written by Matthew Barclay and Philip Hines

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Track II  
Sustainable Systems







## A workforce for primary healthcare

### Training, attractiveness and skill-mix

Organised by the Austrian Ministry of Labour, Social Affairs, Health and Consumer Protection & 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 role of health professionals is crucial for new models of care as the focus across Europe is shifting from a specialised healthcare to a patient-centered primary healthcare (PHC). The need for innovation and new solutions in PHC meets with challenges related to recruiting, retaining and training health professionals in the field.

This workshop, co-moderated by Matthias Wismar, Senior Health Policy Analyst at the European Observatory on Health Systems and Policies and Stefan Eichwalder, Expert at the Federal Ministry of Labour, Social Affairs, Health and Consumer Protection in Austria, explored how PHC and health professionals' skills, competences, motivation and attitudes might be influenced by a renewed focus on training, attractiveness and skill-mix.

### The challenges of PHC and necessary reforms to tackle them

Clemens Martin Auer, EHFG President, highlighted some challenges in the Austrian context that are shared by many European countries: (1) the PHC sector is lagging behind the specialised healthcare sector in funding and innovation, (2) the attractiveness and prestige of working in PHC is low and many of the currently active healthcare professionals in PHC will soon retire, (3) there is a lack of educational curricula specifically for nurses and doctors in PHC, and (4) there is a great need for investment and innovation in PHC. Auer finally underlined that increasing the importance of health professionals in PHC is a truly European topic that is relevant across the continent and should be tackled collectively.



Eichwalder pointed out that the evidence about the need for a strong PHC sector is nearly conclusive, and brought the importance of implementing reforms and novel strategies to the audience's attention. He emphasised the need for increased funding and wise spending though success is contingent upon more than just economic support. He also underlined the necessity to encourage health professionals to work in PHC, as reforms will remain meaningless if health professionals are not motivated to work in the field. This sentiment echoed EHFG President Auer's statement: it needs to be cool to work in PHC!

### Choosing PHC as a career path

Marieke Kroezen, Project Manager at The Erasmus Medical Centre, referred to these challenges and offered solutions for shortages in general practitioners (mainly related to aging and to maldistribution of workforce between urban and rural areas). Based on data from medical students and medical doctors, she suggested that exposing medical students to primary care through compulsory electives and training proves to be a successful intervention for recruiting health professionals to PHC. Multidisciplinary collaborations, use of new technologies and opportunities for career development also seem to influence career choices among emerging professionals. She further evidenced that opportunities for professional development are especially relevant for nurses when choosing to work in PHC. Therefore, tackling the perceived disadvantages of working in PHC (e.g. lack of peer

support, high administrative workloads, low salaries and low prestige) is crucial.

### Changes in training and professional development are crucial for increasing attractiveness

Anita Charlesworth, Director at The Health Foundation, introduced the topic of education and training. Three main messages were emphasised by Charlesworth and in the subsequent roundtable discussions: firstly, setting and locations of health professionals' training are important for the subsequent decisions on where to practice. In order to reduce attrition, professional training and curricula need to include skills specifically relevant for PHC practice so that professionals feel well equipped for working in this setting. Secondly, PHC needs more funding and infrastructure to support professional development and peer support. Lastly, training for PHC needs to involve a wide range of health professionals and should not be focused exclusively on medical doctors, and needs to be closely linked with career progression and development. European cooperation for the recruitment of health care professionals

To successfully recruit - and retain - health professionals in PHC, Martin Seychell, Deputy Director General for Health and Food Safety at the European Commission, stressed how PHC needs to change to be better for both health professionals and patients. He outlined the problem of fragmented PHC systems and the lack of continuation of care, then introducing

solutions that would improve recruitment and service delivery in PHC.

PHC providers should be coordinators of care, motivating and incentivising young health professionals to choose PHC. To realise this, we need to support them with the tools they need, for instance including new skills in the health professional education such as lifestyle management and motivational communication. In roundtable discussions the political will to change the organisational structure from solo practice towards interdisciplinary cooperation was identified as an important measure. Seychell lastly underlined the importance of seeing recruitment and retention from a European perspective. Changes in one country quickly affect the workforce mobility between countries, making it impossible to plan in isolation.

### **We need to be better at sharing best practices**

The topic of how to better share best practices and what role the EU should play was put on the table by Florin Popa from the Structural Reform Support Service (SRSS) at the European Commission. The roundtable discussants agreed on the need to pay more attention to the efficiency of interventions, and on how these best practices can be shared between countries and stakeholders. The EU can provide platforms and evidence for sharing best practices and can support the stakeholders' implementation of efficient health policy measures.

### **New roles for health professionals and patients**

Everyone agreed that working together is essential, but how to achieve this in practice? Claudia Maier, postdoctoral researcher at the Department of Health Care Management at the Technical University of Berlin, emphasised that one can already witness many changes on the collaboration front. Nurses assume new roles as part of PHC teams, and primary care providers are increasingly involving the population using outreach initiatives such as patient navigators and advising pharmacists. Based on scientific literature and on previous debates, Maier's table introduced new tools for teamworking in PHC, including shared care plans for patients, proper leadership and financing, and the promotion of new roles and new regulatory frameworks.

### **Strengthening the position of PHC through awareness and multidisciplinary cooperation**

The topic of strengthening the position of PHC was introduced by Andrea Siebenhofer-Kroitzsch, Professor at the Institute of

General Medicine and Evidence-based Care Research at the Medical University of Graz. Using the Austrian example, she stressed the importance of achieving specialised titles in PHC not only for medical doctors. Further strategies included image campaigns to increase the public image of PHC, more multidisciplinary cooperation, and the establishment of PHC as an independent provider of community healthcare services through bottom-up networking and inter-disciplinary communication among health professionals.

### **Evidence and innovation to ensure a sustainable PHC workforce**

To secure a sustainable workforce for future PHC requires solving the problems of attractiveness of working in PHC, personnel retention, and new PHC models and competence development. Indeed, the topic of workforce for PHC unites the four EHFG 2018 main topic tracks of Innovation for All; Sustainable Systems; Evidence for Action; and No-one left behind - as it requires evidence and service and recruitment innovation to ensure that sustainable PHC systems leave no-one behind.

Written by Martin Fredheim

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## Knowing When to Partner Accelerating national responses for NCD prevention & control

Organised by WHO, EU-HEM & EHFG



The Sustainable Development Goals (SDGs) include the ambitious goal to reduce Non-Communicable Diseases (NCDs) by one third by 2030. SDG 17 focuses on the aim of creating strong partnerships for achieving all SDGs, including this one. Very recently, the 2018 Political Declaration on NCDs defined 13 additional commitments which will hopefully pave the way ahead. One major change introduced was the upgrade of the previous goal of “4x4” to the new goal of “5x5”: Mental health has been added as a fifth item to the list of NCDs, previously consisting of cardiovascular diseases, cancer, diabetes and chronic respiratory diseases. The list of avoidable risk factors has been extended to now also include air pollution besides the previously included factors of tobacco use, unhealthy diet, physical inactivity and harmful use of alcohol.

### Tackling the social and commercial determinants of health

If we want to reduce the burden of these five NCDs, we need to

tackle these five risk factors. If we want to reduce the prevalence of these five risk factors, we need to tackle the causes of the causes: the Social and Commercial Determinants of Health. For example, if we want to change childhood obesity, we will not succeed by telling children to eat differently. Childhood obesity increases on a social gradient. E.g. in England, childhood obesity in boys is at 14% in the most deprived compared with 8% in the least deprived families. The lower the income, the more likely it is that the children in the family are not consuming enough fruits and vegetables. This cannot be changed through health education alone, because healthy food is more expensive and many families do not even know if they can afford their next meal. Therefore, if we want to tackle childhood obesity, we need to solve its main underlying cause: childhood poverty and social inequality. Unfortunately, some policies have recently been implemented which are likely to increase childhood poverty rather than reduce it. Sir Michael Marmot, Head of the Institute of Health Equity, University College London, emphasised that “social injustice is killing on

a grand scale, [and] the top 1% is very good at avoiding taxes.” But there are also best practice examples: especially the Nordic countries show what can be done to reduce childhood poverty by using the tax and benefit system effectively, and we can learn from them. If we only focus our prevention efforts on behavioural change, we will not be effective, we will not tackle the fundamental drivers and we will not substantially reduce the burden of NCDs. Caring about health means caring about social justice. Caring about social justice means caring about the wider determinants of health.

### Distinguishing between public health friends and foes

NCD prevention covers a wide spectrum across the economy, including a lot of players and stakeholders. Should the public sector partner with the private sector? This is a difficult and controversial question. Some public health professionals want more collaboration and some public health professionals want less collaboration. Another important issue when it comes to partnerships is how to distinguish between friends and foes. As one of the panelists suggested, all those who are contributing are our friends, all those who do not show social responsibility are our foes. But does this statement pass the test of real world challenges? Let us take alcohol as an example. The higher the mean consumption, the higher the proportion of heavy drinkers. From a health perspective, the goal is to reduce the mean consumption. Industry wants the opposite. Understandable, because this public health objective – less consumption – implies making the alcohol industry smaller and less profitable. However, if we want to reach the SDG goal of reducing NCDs by one third, industries like alcohol and food will have to change in a socially responsible manner.

### Cooperation does not imply aligned objectives

Ilona Kickbusch, Director Global Health Centre, Graduate Institute for International and Development Studies, Geneva, suggested we should be more precise when talking about “partnerships” and “the private sector”. She argued that not everything is a partnership: when looking at WHO’s “best buys” – evidence-based, cost-effective preventive measures – we see that they require government action of the kind that many industries will not like, because they will not serve the industry’s primary objective of making profit. For example, restricting marketing of unhealthy food to children does not serve the industry’s interests, but advances public health goals. This reminds us to be careful when choosing partners,

because willingness to cooperate does not automatically imply aligned objectives. Also, “private sector” might be a too general term, for example doctors in many countries work in private practices.

### The health sector as a health determinant

From a low-income country perspective, it is not only poverty at an individual level that is the problem, but also the often substantially underfunded healthcare systems themselves. In many instances, healthcare services are still vertically focused on single diseases like HIV/AIDS or tuberculosis, mainly because global funding was available for these specific areas. This kind of funding is not available yet for NCDs or for horizontal health systems strengthening. The panelists considered that strengthening the general funding of WHO was a suitable option for addressing these problems, highlighting the key role of the health sector itself as a social determinant of health and a steward for policy coherence and universal health coverage, so “no one is left behind.” The expected global focus on PHC and UHC in the coming years was perceived as encouraging, as was hearing that partnerships with patients are increasing. The WHO GCM also announced a promising initiative in the form of a “Knowledge Action Portal” ([www.who.int/kap](http://www.who.int/kap)), a community-driven platform created for NCD interaction, information and inspiration that will be launched on 15 November 2018. The platform will present users with an innovative way to enhance global understanding, interaction, and engagement across sectors for the purpose of fulfilling existing – and initiating new – commitments to NCD prevention and control, created for and with those wishing to find the common goals to beat NCDs.

Written by Florian Stigler

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## A new era for Alzheimer's Are EU healthcare systems ready for medical innovation?

Organised by BIOGEN



Alzheimer's disease (AD) is a progressive neurodegenerative disorder that leads to cognitive and functional decline, resulting in Alzheimer's dementia and premature death. It is the most common neurodegenerative disorder in elderly populations.

There is cautious optimism amongst researchers that one or more disease-modifying therapies for AD could become available in the near future. Such therapies could provide patients and their families with a treatment that delays or prevents the progression of cognitive impairment leading to dementia. However, the possible availability of such preventative treatment also implies the need to screen, diagnose, and potentially treat a large population of patients with mild cognitive impairment (MCI). The workshop "A new era for Alzheimer's - Are EU healthcare systems ready for medical innovation?" was opened by Philipp von Rosenstiel, Senior Medical Director, Biogen. In 2018, Biogen sponsored a RAND

policy report examining the preparedness of health systems in six European countries (Germany, France, Italy, Spain, UK and Sweden). How well would these countries be able to face challenges introduced by the availability of a preventative treatment for AD?

The workshop brought leading patient, academia, policy and industry voices together, and Antonia Croy, President, "Alzheimer's Austria" opened the debate. She explained how AD represents a constantly growing challenge for patients and their families. Even before the development of MCI and dementia, AD related disorders have a profound impact on the daily life of those affected, as well as on their caregivers - predominantly female relatives. Health professionals are not trained to advise patients and families on general strategies for coping with new and challenging situations that are often a source of conflict. As president of a patients' association and close relative of an AD-affected person, Antonia Croy



openly criticised the general tendency to infantilise persons with cognitive disorders, always addressing them as patients, but never as persons. Moreover, Croy pointed to some of the emerging trends in the Austrian healthcare pathway for people with dementia: firstly, feelings of shame and inadequacy can affect care seeking by the patient and therefore limit his or her access to the healthcare system. Furthermore, when a person in the early stages of cognitive impairment visits a GP, he or she is often confronted with the lack of preparedness of the health professional. In rural areas with a chronic paucity of health professionals this overall trend can be even more pronounced.

Joint efforts from civil society and different stakeholders are needed to provide people living with dementia with the necessary support, empowering them to live in the community and to fully express themselves. Until today, there is no model for post-diagnosis support in Austria and all relies on voluntary associations. Since 1990, Alzheimer's Austria has supported and assisted people with dementia and their families. The association provides information and consulting, trying to make their voice reach relevant stakeholders. Croy concluded her presentation by underlining the importance of patients' participation in healthcare, referring to the notion of "nothing about us, without us".

Soeren Mattke, Director, Centre for Improving Chronic Illness Care, University of Southern California, outlined the main findings of the RAND report on health systems preparedness with regard to Alzheimer's treatment. Some of the countries studied in the simulation are affected by a chronic shortage of health professionals specialised in neurodegenerative diseases, which can cause long waiting times for treatment. Diagnosis seems to pose less of a problem: findings show that biomarker testing to identify pre-dementia Alzheimer's patients can, in most instances, be conducted by a GP. However, Mattke warned that while some measures to increase preparedness have recently been put in place in the countries studied, they only address a small burden of the current needs in dementia care. The delivery infrastructure is not yet ready, and more health providers have to be trained in the forthcoming years.

In the panel discussion, Claudia Habl, Head of International Affairs and Consultancy, Austrian Public Health Institute (GÖG), stressed that in Austria, where many specialists have

a complementary specialisation in geriatrics, the challenge for the workforce might be smaller compared to the countries analysed in the report. Nevertheless, the increasing age of healthcare professionals means that the sustainability of the system is uncertain. Habl also pointed out that today, the main issue in dementia care in Austria is delayed diagnosis - which would be a serious obstacle to efficient treatment even with new treatment options becoming available. Marianne Takki, Policy Coordinator, DG SANTE, EC, explained how the EU encourages the development and implementation of cross-country programmes and collaborations. She stressed that in this context, it is important that MS define and align goals for innovations in screening and treatment.

Raphael Wittenberg, Associate Professorial Research Fellow, London School of Economics, reminded the audience that health systems have to make evidence-based plans, also taking into account the cost-effectiveness of new treatments. Sarah Neville, Global Pharmaceuticals Editor, The Financial Times, added that high costs of a new treatment could divert increasing sums of money from ordinary care, which is a prerequisite for enabling people affected by AD to have a good quality of life and contributes to containing health expenditures. However, when calculating cost-effectiveness, informal care is often not factored in - but should be, as it accounts for 45% of Alzheimer's care today.

The debate made clear that European health systems need to define clear goals for the care of AD patients in the forthcoming years. Besides considering efficacy, cost-effectiveness and sustainability, stakeholders and decision-makers need to give voice to patients and grant fair access to care, as well as to foster prevention and health promotion in the general population. Also, the societal perspective of the disease needs to be acknowledged to be able to guarantee higher living standards for those affected by it.

Written by Damiano Cerasuolo and Durdica Marosevic

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## Health, Data, Ethics: A European Journey

### More Trust, More Data, Better Health

Organised by Microsoft



Big data, increased computing power and better algorithms translate into greater potential for using data to overcome health system challenges and to provide more personalised, higher quality care for patients. But with these big potential benefits come big potential risks. This discussion between panellists from the private sector, NGOs, academia and government provided a fascinating insight into the trade-offs between potential risks and innovation opportunities ahead of the EU electoral cycle which begins at the end of 2018.

#### Big data, big potential

Cornelia Kutterer, Senior Director, EU Government Affairs, AI & Privacy and Digital Policies, Microsoft, began the panel discussion by describing how transformation across the health industry is critical to improving well-being around the world. Using the right data effectively has the potential to

enhance the productiveness of existing processes, as well as to respond to emerging challenges to the healthcare system, such as ageing populations, the shortage of healthcare workers, rising patient expectations and cybersecurity risks. Moreover, large-scale, real-time data can support a continuous, collaborative approach to healthcare innovation that focuses on preventative care as well as treatment. Indeed, for Magda Rosenmoller, Professor, Centre for Research in Healthcare Innovation Management, IESE Business School, the potential benefit of European-wide health data and AI is so big that to not harness it would be unethical. In order to harness this benefit, the appropriate data system infrastructure needs to be in place, as well as a regulatory infrastructure that can foster innovation. Cross-Europe sharing is key in order to unlock the potential of data emerging from economies of scale.

## Risks and responsibilities

However, all panellists emphasised the risks inherent in the collection, storage, and use of sensitive information. Tamsin Rose, Senior Fellow, Friends of Europe, highlighted concrete examples, including health data being used to check immigration status, and the use of health data during criminal justice procedures. Panellists discussed the ethics behind making profit from patient data. While most agreed that profit from healthcare is not inherently unethical, and is sometimes necessary to foster innovation, the potential for profit-making highlights the need for robust regulatory frameworks to prevent misuse.

## Transparency and trust

Robert Madelin, Chairman, Fipra International, described how Microsoft's Europe-wide consultation on data ethics revealed the importance of going beyond regulatory requirements, rebuilding trust through transparency and patient involvement. All panellists emphasised the critical role for governments to create the right regulatory balance to ensure trust, while supporting innovation. Franz Leisch, CEO, ELGA GmbH, described the Austrian 'opt-out' data storage system, where citizens are informed of the exact ways in which their data should be used.

As advances in health technology, such as personalised genetic testing, become more available, policymakers will need to ensure regulatory frameworks progress at the same rate. For instance, gaining consent for collecting an individual's genetic data may impact other family members. We will need to ensure our notions of 'informed consent' measure up to emerging technologies.

## Conclusions: "Giving data should be like giving blood"

Data has huge potential to improve the efficiency and quality of healthcare across Europe. But the ethical, practical and legal structures that are necessary for this to be harnessed need to evolve in tandem with advances in data technology. Rules and structures for informed consent and the ethical use of data are essential in order for patients to understand how their data will be stored and used, and to rebuild trust in these complex systems. Parallels could be drawn between how to foster trust in the medical profession: patients trust doctors because there is standardised training, ethical standards, and regulatory oversight – the same should be true for data governance. Moreover, standardised structures will help

facilitate cross-border data sharing and research cooperation to harness the potential from economies of scale. Finally, regulatory structures should aim to achieve a balance between ensuring accountability and trust, while supporting innovation. To create innovative data combinations and decrease investments, big data is often shared amongst organisations, crossing organisational boundaries. Big data's principle of data maximisation and open-ended purpose clashes with data protection regulations. This regulation/innovation interface is mutual and dynamic, and there is therefore a strong case for government leadership and centralised governance structures to mitigate risks and ensure ethical standards across Europe.

Written by Alice Walker

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## IP: Barrier or Creator of Sustainable Healthcare?

Organised by Pfizer, Vital Transformation and US Chamber of Commerce



U.S. CHAMBER OF COMMERCE

Intellectual property (IP) rights are the catalysts of innovation in medical industries, research and development, and simultaneously represent the most important bases for commercial business models, trademarks and trade secrets. However, if we were to compare the perception of IP and its status in the EU and the US, there is a very clear discrepancy, especially speaking in the context of small and mid-size biotech companies. Namely, while in the US the medical biotech companies are being supported by many forms of private investment, the situation in Europe is somewhat different.

The first breakfast session at this year's EHFG was designed to talk about the issues surrounding the topic of IP in the EU, introducing the topics of the role of public and private funding, the drivers of success that impact big high-growth companies,

the current international debate on pricing and IP in the biopharmaceutical sector, as well as the aforementioned gap emerging between EU, US and Chinese IP productivity in healthcare.

The moderator Duane Schulthess, Managing Director, Vital Transformation, opened the discussion with a presentation of the results from recent Vital Transformation research aimed at detecting the success factors of IP in Europe. Schulthess invited the audience to perceive IP as biotech, minding the fact that it supports an ecosystem in which investors are willing to lose everything 92% of the time in order to fund the 8% of medicines that succeed in making it to market. In addition to being extremely risky, the funding of biotech requires a lot of capital, making the losses potentially devastating. Additionally, according to findings from research conducted in the US a



couple of years ago, the number one indicator for the success of a biotech company was the size of its stock market listing (IPO). Looking at this study, Vital Transformation wanted to apply the same research mechanisms to Europe and detect the most important indicators for the success (or failure) of European biotech companies.

The research started with an analysis of all European biotech startups that were based in the UK, the Netherlands, Spain or Belgium and registered between 2001-2007, assessing their development until September 2018. The methodology was based on comparing the impact of IPOs, private investments and EU funding on the success or failure of a company. With private investment exceeding \$30 billion USD, the IPO reaching up to \$1.2 billion USD, and \$61 million USD coming directly from the EC, it was clear that biotech companies in Europe are heavily dependent on investment from the private sector.

It was found that total private funding is statistically significant to the success of biotech companies, as well as that EU funding is not statistically significant. However, there was a clear correlation between the EU and private funding, essentially showing that private money can with certainty predict the EC investment in biotech. Finally, it was clearly shown that the IPOs don't statistically impact the success of EU companies, which was concluded to be the reason why

Europe loses biotech companies to the US as soon as they mature. To conclude, "the Market" decides which companies will be successful by allocating resources.

Introducing the panel, Schulthess asked them to comment on the findings.

### The experience of a small biotech company

Emil Pot, European Patient Attorney, NLO, told a story depicting a personal experience with owning a biotech company in Europe. His company was founded in Belgium in 2006. However, in 2015, he had to sell the company because it was not possible to raise sufficient capital in the EU to proceed with the phase three of clinical research. The company was sold to a US buyer as the only remaining solution to their survival.

### Big Pharma Input

Eva Grut-Aandahl, Head of European Government Affairs, Pfizer, pointed out that Pfizer, operating in innovation sales, biosimilars and generics, does invest in research – with numbers as high as \$8 billion USD yearly – while building strategic partnerships with small companies and universities. Still, what is clear is that Pfizer also participates in acquisitions of small and mid-size biotech companies once they lose their financing sources, this way simultaneously playing the role of a saviour of a company, and an enabler of the trend of EU companies moving to the US.



## Innovate the innovation

The patient representative on the panel, Nicola Bedlington, Secretary General, European Patients' Forum, widened the discussion from a merely market-centred point of view to the issues that concern everyone. There is a clear need for a fair framework within which value and pricing discussions can be held, which will also provide for increased efficiency. To tackle this and make it more effective, the system needs to innovate the innovation process – this is where patients are key. Bedlington later remarked during Q&A that in addition to a stock-market report, the EC should look into innovative medicines' initiatives and draw lessons on how to develop innovation in a smart and savvy way, taking PPPs very seriously. Data (both regarding transparency in pricing and market access) should be accessible to everyone, helping to ensure product access. Finally, the EC should be responsible for educating the MS governments on how to create better and more enabling conditions.

## (Re-)defining IP

Yannis Natsis, Policy Manager for Universal Access & Affordable Medicines, EPHA, pointed out the fallacies of patenting systems, stating that the criteria are just not specific or strict enough, leaving significant leeway for patenting everything from dosage to pathways and similar components of medicine distribution. In other words, there is a need for a redefinition of what IP is, and there is a need for limitations on IP. Additionally, the top priority of big pharma should switch from profit and capital to access to medicines for all patients, and this should be done by considering the pricing and possibility of strengthening competition while minding the innovation processes.

## Single dedicated market for innovation

However, taking all these points into account, there remains an issue of why the innovation and inventions from the EU leave Europe as soon as they become successful, and even more importantly, whose is the biggest responsibility to react and how. In Pot's experience, there is enough capital in Europe, but it is just not streamlined towards IP and innovation. Whilst there is competition, its existence is insufficient if it is not supported by capital, because then companies simply lack the means to progress. One solution to this issue could be the aforementioned market solution – there should be a true single dedicated market for innovation at the EU level, which would allow for secure and non-risky IPO trade. The failings that we

see now are the result of bureaucracy which is preventing “true capitalism” from flourishing, which can be exemplified by the issue of drugs approval: as a rule, medicines that are made in Europe receive their approval in the US before they do in the EU. Namely, as Grut-Aandhal pointed out, although the EU has all the characteristics required for leadership, innovation and production, there is a problem of national regulatory issues.

## New hope for the next EC?

With a discussion that was essentially based on the opposition of the responsibilities of the private and public sector with regards to IP in Europe, both sides made some very strong points: the great ‘brain drain’ of successful small and mid-size European biotech companies is a fact and a great loss for both the EU economy and healthcare. The responsibility for this lies clearly both in the private and public sector. Namely, while the private sector is insisting on patenting everything, starting from the actual medicines through to medical pathways, dosage, and many other components of medicines production and distribution, making it extremely difficult to further drive innovation, the public sector is failing innovation by grinding it through too many bureaucratic streams, which slows it down and creates high amounts of waste, both in terms of resources and time. With the new EC in 2019, there should be more initiatives for different level PPPs, which would enable greater satisfaction at all levels, keeping the innovative companies in the EU, delivering medicines in a timely and affordable manner, while still enabling reasonable profit-making by pharmaceutical companies.

Written by Alberto Mateo and Lilian van der Ven

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## Patient insights for sustainable care Improving efficiency in care for all

Organised by All.Can | Secretariat represented by The Health Policy Partnership



Whose perspective should be central to the way we plan and deliver care? It does not matter who you direct this question to, patient or healthcare professional, you will probably always get the same answer: the patient. Yet, given the complexity of the healthcare delivery process, patients, despite their key status, are often relegated to a rather unempowered and passive role. This is precisely one of the issues on All.Can's radar.

### Together we all can

Since it was established in 2017, the All.Can multi-stakeholder initiative has aimed to identify ways in which the use of resources for cancer care can be optimised. All.Can's members include pharmaceutical companies, radiotherapy providers, patient organisations and data companies among others.

No stranger to the European Health Forum Gastein, All.Can already participated in the 2017 conference in a session entitled "Making cancer care more efficient – What role can different stakeholders play?" The purpose of this year's session was to explore how patient insights and experiences can be converted into evidence to drive policy change. The lessons learned taking cancer as a case study will then be used for

other chronic conditions. During her opening speech, Kathy Oliver, Chair and Co-Director, International Brain Tumour Alliance, advanced the session's key message by stating that if the audience could take one thing away from the session, it should be the idea that "efficiency has to be defined based on what matters most to patients". She added that despite the apparent magnitude of this objective, it can often be achieved through very simple innovations, and conveyed this idea through a heartwarming example: a ball of yarn used to connect children to their parents while they are undergoing radiotherapy treatment. The cost of the ball of yarn was a mere 1.50 GBP.

### Patients' voices heard: the All.Can survey

Daniel Ratchford, Chief Executive Officer, Quality Health, was the next speaker to take the floor. He went on to present the interim findings of the All.Can survey, which is led by his institution. Consisting of an international version and ten other country specific versions, the All.Can patient questionnaire focuses on waste and inefficiency through both open and closed questions and can be accessed through the All.Can

website. The final results will be published and a report will be launched at the EP on the 7th February 2019. The survey's interim results are already meaningful, as they revealed that the top inefficiencies in care identified by patients are consistently the same across the surveyed countries, namely:

**Diagnosis:** inefficiencies in the time taken to see their doctor, referral for diagnosis, waiting for test results or waiting for a treatment to start. What is particularly worrying is that many patients were misdiagnosed once (or a number of times) before their final cancer diagnosis.

**Lack of psychological support:** not only for patients themselves but also for their families. From the two thirds of respondents that considered themselves in need of some sort of psychological support throughout their diagnosis, at least a third stated that it was unavailable.

**Time management:** many patients highlighted frustrations and inefficiencies in appointment and time management for ongoing cancer treatment. For example, many complained that they had had appointments cancelled by the hospital or clinic, and that confirming and changing appointments is still often carried out on paper or by post.

**Financial toxicity:** the financial implications of cancer treatment, which are generally ignored by care providers, were also one of the pressing points presented by patients. While the purchasing of additional medicines or the loss of employment are costs that public health professionals are more than aware of, case studies of other costs such as transport or childcare were also presented.

Ratchford's presentation was followed by interactive groupwork in which each table was prompted to develop an elevator speech to persuade policymakers to work on one of the issues identified by the survey. Session attendees with different backgrounds were able to interact and then share their ideas with the rest of the audience, in an exercise where benchmarking and exchange of successful experiences across Europe were very present.

### A consensus on sustainability

The session ended with a discussion where policymakers, cancer professionals, cancer patients and the medical industry were represented. Several arguments for sustainability were put forward. Dirk Van Den Steen, Policy Office, DG

SANTE, EC, cited a 2017 OECD report that states that up to 20% of all spending on healthcare across Europe can be wasteful, which means there is great potential for working on improving efficiencies in care, particularly if the growing budget pressure that follows European demographic change is taken into consideration. Other panelists added that there should be more research on where money is being wasted. The importance of using the latest data and digitalising health systems for better policymaking and transparency was also highlighted.

A call for a more holistic approach was issued by all panelists and championed particularly by the industry and professional representatives, once again highlighting the importance of data standardisation, support for digitalised systems and engagement of all care professionals including but not limited to oncologists, social workers and specialised nurses in the caregiving process.

### Key take-home messages

- Efficiency must be redefined based on what matters most to patients. The costs to the patient, whether measured in time or currency, must be taken into consideration.
- Pending the All.Can survey's final results, the issues that patients across Europe find most pressing in cancer care relate to the diagnosis, financial toxicity, time management and lack of psychological support.
- There is both need and room for improvement when it comes to spending in healthcare. Patient experience is a powerful resource that policymakers should tap into. Long term sustainability is a matter of intergenerational fairness.
- A holistic take on cancer care is the right path to restore the patient to a central role in the care process.
- We must be bold and enact what the European Bill of Cancer Patients' Rights says so that all cancer patients across Europe get the treatment they expect and deserve. Best practices saves lives.

Written by Julio Muñoz

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## Setting priorities for public health in the EU Steering Group on Promotion and Prevention

Organised by DG SANTE, European Commission



The European Commission (EC) has recently set up a new approach for supporting Member States in further accelerating their progress on the Sustainable Development Goals (SDGs) across the EU Member States, particularly those related to non-communicable diseases (NCDs), and to address some of the weaknesses of the EC's previous efforts. This is now being pursued through a newly established Steering Group on Promotion and Prevention (SGPP). The workshop aimed at showcasing the work and ambition of SGPP and the opportunities it brings to all interested stakeholders and parties.

### SGPP and its activities

John Ryan, Director, Public health, country knowledge, crisis management, DG SANTE, European Commission, kicked off by presenting the history of the new Steering Group and its

three-fold aim of selecting and supporting the implementation of best practices, providing early stage coordination of health investments and providing strategic orientation in health.

There was a notable emphasis on SGPP being different from past EC initiatives –more open to true collaboration and Member State leadership. Instead of a top-down approach to adopt specific models, it allows the EU members to firstly identify their own priorities, secondly select from a range of applicable evidence-based policy interventions, and, lastly, have access to the necessary assistance and expertise in new policy implementation. The EC provides new tools, including its best practice portal, or targeted policy briefs from the Joint Research Centre (JRC) or via expertise from other partners or other EC activities and institutions. John Ryan introduced the SGPP as a body to streamline all EC activities on public health



in a coherent and centralised approach. Yet, there was a call for a mechanism that could solve the ongoing confusion of Member States or other stakeholders concerning different funding options and how Member States can best access them.

### Best practice examples - and the necessary ingredients for success

Among the soon-to-be-launched best case examples three remarkable plans for new public health initiatives were presented: one best practice example from Romania on colorectal cancer screening, presented by Corina Silvia Pop, State Secretary for Health, Ministry of Health, Romania; a case from Italy on cardiovascular screening by Giovanni Nicoletti, Senior Medical Officer, Ministry of Health, Italy; and an example from Sweden on physical activity on prescription presented by Marita Friberg, analyst, Public Health Agency, Sweden.

The speakers displayed a sense of genuine enthusiasm about being able to take the lead as Member States on defining the key problems that need to be addressed. Some, however, conceded that the scheme is in its infancy and its success will depend on the people implementing the programmes, and on their dedication. The programme was presented as a good testing ground for small projects that typically start off on a local or regional level. It was acknowledged, however, that the adaption of any pilot had to be 'smart' - not simply by copying best practices but adapting them to the local population and its needs whilst preserving all the vital programme aspects.

Interestingly, some speakers, such as Giovanni Nicoletti, regarded this mechanism also an opportunity for domestic scaling. If a project is successfully tested in a very diverse, international setting, it will supply local or regional institutions with more political capital and further evidence to push for the programme implementation locally and potentially convince sceptical decision-makers.

Many attendees recommended for every project to include the best Member State case study as well as several other Member State partners. This would create an environment for cross-border learning at a time when we still lack sufficient channels.

### SGPP as a link to other EC institutions

Following the introduction of best practices, a range of

speakers introduced other European institutions or EC teams related to the SGPP.

Florin Popa, Structural Reform Support Service (SRSS), European Commission, presented the SRSS, a programme that aims to ensure that Member States, after having identified the right initiative and having secured the funding to roll it out, do not fail at the crucial last stage of implementation. The SRSS provides support and builds the Member States' capacity to implement the pilot or the full new initiative.

Dorothee Eckertz, Lead Health Economist, European Investment Bank, showcased another important aspect of the SGPP – that of becoming the engagement and consultation forum for resolving key questions of emerging healthcare needs and treatments, such as proton therapy treatment centres. Eckertz urged to make better use of European funding as a catalyst for new technologies.

### A sneak peek of where the SGPP could go

But are the SGPP and its initiatives such a "miracle" as Corina Pop called them? As the workshop moderator Martin McKee, Professor of European Public Health, London School of Hygiene and Tropical Medicine, rightly asked: what happens if Member States do not consider an important issue their priority? Will it never be addressed? In response, Dirk Van Den Steen, Policy Officer, DG SANTE, European Commission, reminded all of the existence of EC 'safety mechanisms', such as the European Semester and its healthcare system-related recommendations.

The workshop served as a comprehensive sneak peek of the potential impact a well-run Steering Group could have on pan-European health policy interventions. However – similarly as for its best case initiatives – the SGPP needs to be tested and evaluated before we can judge its success beyond initial small

Written by Petronille Bogaert and Rozalie Horka

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## All Policies for a Healthy Europe

### A multi-stakeholder vision for a Europe that is Big on Health (2020-25)

Organised by Johnson & Johnson



How can sectors come together for healthier policy? Can an 'all policies'-approach unlock a pro-health vision for European stakeholders? This forum session set out to explore how all actors in society, be it public or private, can contribute to a healthy and sustainable Europe by putting health at the core of what they do.

In order to improve health and well-being of European citizens, actions of the public and private sector need to focus on creating and sustaining three fundamental pillars: healthy societies, a healthy environment and healthy systems.

The forum was divided into two sections, combining an expert panel with interactive involvement of the audience. During the first part, panellists discussed current challenges and opportunities related to building a Europe where health is

at the front and centre of every policy. During the second part, the audience worked together in groups to develop ideas on how this vision could be realised.

#### Where do we want to go?

There was strong agreement among panellists that the vision of a healthy Europe can only be achieved by tackling the wider determinants of health as well as health inequalities. Yet, while this insight seems to be understood as common sense among policymakers and practitioners during debates, concrete action is often lacking.

As Rachel Dunscombe, CEO, NHS Digital Academy, pointed out, the three most impactful interventions to promote health in European countries are to improve education, enhance employment conditions and ensure affordable and safe



housing. However, these determinants of health can only be addressed through an enabling and equitable infrastructure. Every sector and every stakeholder can play their part in creating such fair conditions.

The most vulnerable groups of people are the ones most affected by health inequalities, and targeted and sustained efforts are needed to improve their health. The needs of the vulnerable concern the whole of society: Caroline Costongs, Director, EuroHealthNet, highlighted the importance of acknowledging that only a whole-of-population approach can be sustainable in the long run, as the social gradient affects the entire population.

### What are our challenges?

Achieving healthy societies, environment and systems is an ambitious task that faces major barriers in the current economic and political context. Erika Widegren, Chief Executive, Re-Imagine Europe, explained that currently one of the biggest challenges is that economic prosperity does not necessarily correlate with health improvement.

As such, Europe is a wealthy but unhealthy continent, with rising rates of obesity and depression. This may partly stem from a lack of understanding of how health can be an asset for the economy. For example, when international trade deals are negotiated, economic interests are largely prioritised over health impact. Public health professionals need to play an important role in changing this narrative.

As Zoltan Massay-Kosubek, European Public Health Alliance, stressed, it is the job of public health professionals to explain the health narrative to actors from outside the health context. In the past, this has been done with limited success, which may explain in part why decades after the Alma-Ata Declaration or the Ottawa Charter, "Health in all policies" has not yet become a reality.

### Which opportunities do we need to seize?

Whilst important barriers need to be overcome to achieve a healthy and sustainable Europe, we also need to take full advantage of current opportunities. Caroline Costongs highlighted the European Pillar of Social Rights and its proclamation of 20 principles for a fairer, more inclusive European Union embraced by the European Commission, Parliament and Council. These principles, addressing a broad

range of wider determinants of health, include, for instance, the right to access healthcare and the right to secure and adaptable employment and fair wages. This is only one example of an important window of opportunity, which could be used by public health agents to advocate for policies that improve health and reduce inequalities.

Another set of opportunities is linked to new technologies and big data. Rachel Dunscombe, CEO of the NHS Digital Academy, elaborated on ways data and technology can be used to improve population health. By collating and analysing data from various sources, health systems can individualise interventions, leading to fully patient-centred care. For example, alcohol consumption data could help to maximise the efficiency of public health programs by targeting interventions to those living in the most affected areas. However, there are two factors to take into consideration to capitalise on this opportunity in an ethical manner: Firstly, informed consent is needed to collect data, which is often difficult to obtain from large groups of people. Secondly, in order to take advantage of the variety of data sources, data needs to be stored in an open and standardised format, which is currently not always the case.

Additionally, Zeger Vercouteren, Vice President Government Affairs & Policy, Johnson & Johnson EMEA, explained that employers can act as an important agent of change in improving the health of the population by improving the health of their employees. Employers need to realise that it is in their very own interest to have a healthy workforce. This message is slowly reaching different companies, Vercouteren asserted, but substantial efforts still need to be made. For example, Johnson & Johnson has launched campaigns to prevent seasonal diseases such as the flu. They are further aiming at minimising the company's environmental impact by reducing waste. Vercouteren believes that a company like Johnson & Johnson, which is employing thousands of people, can act as a kind of "laboratory" where the effectiveness and efficiency of public health interventions can be tested.

### Towards a healthy Europe – EHFG delegates weigh in

During the second part of the forum, the audience worked together in groups to come up with three concrete actions to realise healthy societies, a healthy environment and healthy systems. Joseph Elborn, president of the European Health Parliament, kicked off the group work with an input speech

on the recommendations that his organisation, made up of young public health professionals, gave to the European Parliament. These included pharmacists being incentivised to administer vaccines at walk-in services, EU action to reduce meat consumption in the population, and a higher proportion of funding being allocated for preventive services.

With these examples in mind, the different groups started to consider what advice they would give to policymakers in Europe. After lively debate both on which broad areas to focus on and which specific recommendations to choose, the different table groups submitted recommendations ranging from education programmes to social policies. At the end, the audience voted via the online-tool Wisembly for the recommendations they deemed the most effective and feasible ones to improve each of the three pillars.

To create healthy societies, the audience voted for a more comprehensive health education programme in schools. Such a programme should empower children to learn about health in general, but also promote the development of specific skills like cooking. A second recommendation focused on a standardised food-labelling format, which, building from best practices, could help consumers choose the healthiest products. Finally, acknowledging the role of employers in improving population health, the audience recommended the introduction of annual corporate reports on the policies being implemented in companies to improve the physical and mental well-being of their employees.

To create a healthy environment, the audience made recommendations on how to make cities less car-dependent and to reduce the impact of transport on the environment. Three specific recommendations were made: (i) cities should set goals which incentivise them to make public transport environmentally friendly, e.g. by using emission-free vehicles or offering affordable public transport fares; (ii) administrative bodies should collaborate with renewable energy companies to promote eco-friendly public transport; and (iii) stricter air quality regulations should be implemented, encouraging cities to increase pedestrian and green zones.

Finally, in order to create healthy systems, the audience agreed on the need for a wider health promotion framework at schools connected to the suggestion of comprehensive health education. With regard to technology, the audience voted for

the development of a cloud-based European Digital Health passport, which enables data sharing. This passport could be used to gain more insights into the health of the population and to develop individualised, more efficient public health interventions.

### The road ahead

Without a doubt, to create a healthy and sustainable Europe, we must act on the wider determinants of health. Conclusions of this session outline steps we can take to succeed: Firstly, we need to use existing examples of good public health practice when communicating the importance of health to non-health actors, and we need champions and change agents who take on leadership in demonstrating the value that prioritising health can bring for all stakeholders. Secondly, it is important that all stakeholders come together and use existing tools and technology as well as new channels to innovate and advocate for effective public health policies. Outcomes of the session will be taken forward in the further development of a multi-sectorial initiative for shared advocacy on health and well-being in the lead up to the European elections.

Written by Alberto Mateo and Ramona Ludolph

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## Policy in Evidence - Re-examining the connection

### How to use evidence the smart way

Organised by Gesundheit Österreich GmbH (GÖG) & European Observatory on Health Systems and Policies

Gesundheit Österreich  
GmbH

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

Policymakers and researchers have different ideas of what counts as good evidence, which results in key actors paying attention to different types of evidence. Where there was once a knowledge gap, there is now an information overload that challenges decision-makers in the policymaking sphere to choose evidence and tune out the noise. Yet, healthcare and politics are intertwined, and the political process is complex and not easily controlled.

Keynote speaker Paul Cairney, Professor of Politics and Public Policy, University of Stirling, UK, encouraged researchers to work out where the action is to make policymakers more receptive to their evidence. It is key to understand where change happens and the rules (institutions) – formal and informal – that govern networks. It is essential to learn the different language currencies (ideas) that govern healthcare, research, and policymaking. Cairney also pointed to the importance of building trust and forming alliances (networks) that capture input at all levels of policymaking to better process information. Remaining alert for windows of opportunity to

influence organisations, not just individuals – which do not occur frequently in political systems – is imperative. All these processes require a major investment of time and an increased need for evidence synthesisers who are not only skilled in knowledge translation but who can help to contextualise the evidence.

A central challenge in calibrating the values of researchers and policymakers stems from agreeing on the root question to investigate. There is a wealth of evidence to identify problems but much less evidence available on how to solve them. The scientific identity of researchers tends to be objective and often does not cross the line from the what to the how. Researchers are not often asked to find yes or no answers as evidence depends on the context, while policymakers are asked to consider all aspects, weigh and appraise values, make decisions based on the evidence, and give yes or no answers. As an experienced former Minister of Health of Slovenia, Milojka Kolar Celarc reminded the audience that policymakers work with the double constraint of vast availability of



evidence and the need to act fast. As it is often necessary to negotiate across ministries to obtain good evidence, personal relationships are important to build trust and networks by working together over time. Brigitte Piso, Head of the Austrian National Institute for Quality in Healthcare (BIQG), Gesundheit Österreich GmbH (GÖG), highlighted that at the end of the day not all questions can be solved by binary answers and therefore value must be placed on the pieces of evidence research can provide. The evidence surrounding an issue then becomes but one piece of the puzzle. This is a call both for policymakers and researchers to cross the line from identifying a problem to making recommendations on how to solve it, which requires a conceptual change from evidence-based to evidence-informed policy and decision-making.

### The need for “glocal” evidence

Useful evidence captures solutions for challenges on a global scale, contextualised for local challenges and local decision-making. Tanja Kuchenmüller, Unit Leader, Division of Information, Evidence, Research and Innovation (DIR), WHO Regional Office for Europe, showcased best practices for knowledge translation including institutionalising capacity building in evidence building, tailored for policymaking. That is, taking the best available global and local evidence, contextualised for local policy and practice levels. This new “glocal” evidence can help facilitate the work of policymakers and create interlinkages with civil society, creating trust and understanding, thereby increasing evidence implementation. Evidence-informed policy vs. evidence-based decision-making requires a conceptual change in thinking that does not always result in policy changes.

### Communicating evidence for action

In an environment where evidence is more often available than not, the conversation is shifting from filling a knowledge gap to curating evidence that is a good fit for the issue at hand. There is an increased need for knowledge translation at the intersection of research and policymaking to help inform decisions from the what to the how. White papers have emerged as flexible narrative tools for summarising the evidence of complex policy issues and presenting multiple perspectives to engage policymakers to practice evidence-informed decision-making.

As Rob Cook, Clinical Director, Economist Intelligence Unit (EIU) on Healthcare Practice, reminded participants, practice

methods need improvement, including better reporting standards, though great advancements have been made in the science and art of this type of communication. Yet, the capacity of developing evidence briefs is an acquired skill that requires peer mentoring and support – an investment in terms of experts and policymakers having time allocated in their work schedules to strengthen these skills.

### Controversies surrounding evidence and policy

Quality health outcomes are intertwined with the political process and how policymaking happens. One of the central controversies in this context is determining who has the responsibility to act as the knowledge broker. Yet, there was an agreement that the role of the knowledge broker is not always to advise which course of action should be taken but instead to provide evidence-informed recommendations as a piece of the evidence decision-makers can use to choose a course of action. There were issues raised around the ethics of using evidence produced by the private sector while keeping in mind that the business sector can often serve as a catalyst for service and innovation in healthcare. However, if the evidence contradicts the political agenda, it can prove difficult for politicians to garner the support of voters and be re-elected.

### One step closer to the “how”

Informal contact or interaction by chance between researchers and policymakers is not enough. This expert panel therefore recommended to incorporate knowledge translation capacities into the training curriculum of both researchers and policymakers. It has been proved to be essential for researchers to know how to present evidence effectively in the context of policymaking. Likewise, it is essential for policymakers to have the appropriate background to select and interpret the evidence being provided. Both need to have time built into their day to practice and strengthen the skills needed to communicate and synthesise evidence. Another recommendation by the panel was to finance knowledge translation platforms between researchers and policymakers from the beginning, resulting in institutionalised mechanisms for knowledge sharing and evidence building.

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Written by Jessily P. Ramirez

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## Global and national health strategies Is there a recipe for success?

Organised by the Swiss Federal Office of Public Health (FOPH) & the European Observatory on Health Systems and Policies



Across many focal topics at the EHFG 2018, one takeaway prevailed: to overcome current challenges, intersectoral action for change is key. Comprehensive integrated strategies are needed to facilitate such collaboration – globally and on the national level, where reforms and policies are often formulated around adapting the goals of international strategies to the national context. But what can we realistically expect from such documents, and how can we ensure delivery on them – is it possible to come up with a cookbook for what makes a strategy poised for success?

At this workshop participants discussed national and international health strategies and engaged in a candid exchange on what worked and what did not in order to identify lessons for the future.

### Implementation and ownership

In his keynote, David Hunter, Institute of Health and Society, Newcastle University, UK, stressed that whether we are talking about policies, plans, reforms or strategies, they are ultimately all designed to change the status quo and meet an identified challenge. The concerns we are facing in national health systems have become remarkably similar and converging – but at the same time remarkably complex.

Operating in a matrix of wicked problems, interconnected systems, multiple layers of governance and dissolution of traditional organisational structures and boundaries is challenging for politicians, public health advocates and civil servants alike. The gap between aspirations and capability, Hunter argued, spells a recipe for implementation failure.

Bridging the operational disconnect between high-level policy formulation and on-the-ground delivery necessitates moving away from 'front end policymaking' that stops where the agenda setting ends - towards equal and early focus on implementation, embedding and monitoring. As the Institute of Public Administration, Ireland, summed up in 2013: 'Many problems that appear as implementation problems are, in fact, problems arising from poor policy formulation that did not take implementation sufficiently into account from the get-go'.

National strategies based on international frameworks also fail if they lack cross-departmental ownership and cannot be buoyed by health ministries alone, Hunter stressed, as examples from the UK and elsewhere demonstrate. Focusing less on changing solely structures, and more on relationships and culture within systems may be key. As Hunter concluded, the 'Hows' of change need to be more prominently considered as compared to the 'What and Whys'.

### **Tight on the ends, loose on the means?**

What is appropriate in an (inter)national plan, needs to be adaptable when implemented at the regional and local level, panelists agreed. Liisa-Maria Voipio-Pulkki, Director General of Strategic Affairs and Chief Medical Officer at the Ministry of Social Affairs and Health, Finland, shared experiences from her country, where in the context of upcoming health systems reforms the state is collating experiences and examples of good practice as packages to serve to regions, including guidelines on data use and ensuring regional digital infrastructure. Additionally, an evaluation framework has been developed and tested alongside the policy formulation, with room to be adapted to each region's needs and to new governance models that include ministries of finance and health as well as regional authorities.

To design successful strategies, it will be necessary to be flexible on the means but uncompromising on the ends we want to reach – whether in leaving room for local adaptation of a strategy, or even in accepting a certain imperfection in the policy process that can never fully reflect a complete balance of all stakeholder opinions while maintaining a strong and recognisable vision. Natasha Azzopardi-Muscat, EUPHA President and Consultant in Public Health Medicine at the Directorate for Health Information and Research, Malta, stressed that while strategies should aim to be inclusive, a plan

that tries to accommodate too closely every possible interest or critique can lose all recognition value and direction. A good strategy, on the other hand is 'something that clearly enables you to do something different: something that can be recalled, and that people feel has an impact'.

When it comes to the process of strategic formulation itself, there may be untapped potential in recognising its benefits. Doing the process well, Azzopardi-Muscat argued, is as valuable as the final document you produce – both in forcing stakeholders to get explicit about political goals and resources needed, and in opening the opportunity to really listen to people, engage, and provide a sense of hope and momentum. As summed up by Nora Kronig Romero, Vice-Director General of the Federal Office of Public Health, Switzerland 'It is not just the strategy or the document itself that makes the difference, but what we do with it.'

### **Money speaks**

Highlighting the Finnish example, Voipio-Pulkki underlined that developing comprehensive reforms of health and social care services that take risks on investing in implementation measures required political will and commitment. When it comes to courting investment, Azzopardi-Muscat maintained that a written strategy itself is a powerful signal – especially for countries that rely on donors and receive funds. Being able to present a strategic document coupled with cost-benefit analysis can be an excellent way to make the case for investment to finance ministries and other budget holders.

Audience members shared successful policy examples where payers used the power of funding to secure rapid implementation, for example a plan to improve primary care performance in the UK where access to funds for the project was made contingent upon full digitalisation of operations by participating GPs. Those making strategy with some fiscal power, session participants agreed, should use it more purposefully and creatively to incentivise progress. On the flipside, we need to interrogate critically how much cost poor governance can add to the health budget.

### **Leadership and disruption**

While fiscal pressures apply even in high-income countries, Clemens Martin Auer, Special Envoy for Health for the Federal Ministry for Labour, Social Affairs, Health and Consumer Protection, Austria, highlighted that even with adequate



funding, the fragmentation of responsibilities remains an issue. Bringing about trans-sectoral ownership of strategies and uniting stakeholders requires clear leadership. Panellists also emphasised that from the perspective of civil servants, election cycles with a new set of priorities by incoming administrations can present a threat to even the best laid plans.

Beyond anticipated election cycles, it is becoming increasingly relevant to design strategies that can be adapted even to major disruptive events - such as recently, Brexit - which may fundamentally change circumstances and pretexts for the implementation of a strategy. Nurturing leadership approaches and learning how to navigate power shifts are becoming increasingly relevant skillsets for public health actors.

### Power to the people

Ultimately, as David Hunter pointed out, every proposition for change and strategy with a chance of success needs to answer the question 'How does this make people's lives better?'. Dheepa Rajan, Health Systems Advisor, WHO, relayed an example from outside of the EU context demonstrating how ownership of a strategy by the population can give it recognition and attention - and help to carry it through changing administrations and shifting politics. The health sector reform in Tunisia closely followed the revolution in 2011, taking place amid a heightened sensitivity by leaders for the need to secure the population's support for any reform efforts. With support from WHO, a societal dialogue for health was carried out, involving in-depth consultation on people's needs and opinions, resulting in a white book combining population input and WHO analysis.

The reform has prevailed despite changing governments and leaders, and results are currently feeding into the development of a new national health strategy - largely due to overwhelming backing by the population. Even though not all public consultations can be as extensive, Rajan argued, securing population buy-in - through consultations, focus groups, using tools like Eurobarometer to our advantage - may help our strategies weather the storm of electoral cycles and high-level changes.

### Lessons learned and the road ahead

Opening the session, David Hunter opined that regarding the effectiveness of strategies, you can either embrace optimism, pessimism or realism - by the end, it seems there is cause for

a little bit of all three.

Reviewing research and experience from a variety of countries, it becomes clear that no health strategy or reform can fully succeed without initial political investment, clear leadership, and ownership of the strategy's goals that transcends departments, ministries and sectors - and, crucially, includes ownership by the population.

With these factors in place, long-term strategies have better odds of withstanding changing political interests - a necessity, as health systems reforms today are so complex that the length of the development and implementation cycle almost always exceeds the parliamentary cycle.

When it comes to the formulation of strategies, we must understand - and leverage - the inherent value of the process, while being rigorous about setting the building blocks for implementation and monitoring already from the start. After all, as Hunter reminded the audience 'Arguably, putting a policy into place is not the end of the journey - it is only the start of it.'

Written by Cara Pries

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## Health as an Asset

### The value of good health for social & economic outcomes

Organised by The Health Foundation

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With a rather illustrious range of speakers from both health and social sciences, this session was always going to provoke much food for thought. The aim of the discussion was for panelists and attendees to engage in a discussion on the complex topic of 'health as an asset'. What does this mean? How can we place this concept at the forefront of society to ensure equal opportunities flourish in all that we do? What barriers need to be overcome to ensure health gains are prioritised in the political sphere?

#### The social and economic value of health

"Health should not be seen as a cost, but as an asset that we can invest in, an opportunity". This statement was made early on by moderator Tim Elwell-Sutton, Assistant Director, Healthy Lives, The Health Foundation, and laid the foundation for the rest of the session. Reflecting on conference discussions so far, he asked the audience to consider how we can change the narrative around investing in health and move beyond preaching to the converted, to those we need to convince beyond the health sector. David Finch Senior Fellow, The Health Foundation, put forward a notion that, when it comes to health, politics is quite short-sighted and often susceptible to changing power structures. This means that often there is no real opportunity to follow through any long-term health programmes that could

benefit the whole nation, and therefore, most politicians focus on policies they can achieve in their term in office.

Alice Sullivan, Professor of Sociology, Centre for Longitudinal Studies, University College London, presented a new project that will study the impact of physical and mental health conditions on later outcomes (in terms of labour market participation, wages and social participation) in three different cohorts of children, born in the UK in 1946, 1958 and 1970. Longitudinal studies have highlighted how health challenges such as obesity and depression are increasing among generations, and the project will aim for a better understanding of these mechanisms that should spur action and can be used to inform targeting of resources. Another policy aim is to better understand how the wider costs of poor health and wider benefits of good health can give impetus to greater investment in tackling health problems.

During a walk-through of the issue of childhood obesity, Franco Sassi, Professor of International Health Policy and Economics, Imperial College London, pointed to evidence suggesting that childhood obesity is strongly associated with socioeconomic status, both in the UK and elsewhere. However, the question of the causal link between childhood obesity and economic

and social outcomes has not yet been satisfactorily answered. The primary goal of the work on childhood obesity that Sassi is leading is to break the vicious circle linking obesity, ill-health and social disadvantage across generations. He hopes that the project will produce evidence that will help to break this cycle and help us to understand the impacts of childhood obesity over the life-course, as well as to strengthen childhood obesity prevention efforts and mitigate its impacts.

### Improving health: lessons from policy and practice

An inspirational presentation from Sir Michael Marmot, Head of the Institute of Health Equity, University College London, shifted the focus to the wider determinants of health, linking economics and health. Health inequalities are unjust and social injustice is killing on a grand scale, asserted Marmot. He showed graphs illustrating widening health inequalities between income groups in the US and UK, where life expectancy is stalling or falling for the poorest. The UK has faced the problem of stalling life expectancy since 2011, and if health is getting worse, then society is getting worse, he postulated. Another key topic revolved around multinational companies' policies of tax avoidance. Marmot stated, "tax havens increase health inequalities". As a consequence, health policymakers need to focus on interventions aimed at tackling economic and political determinants, the major levers able to radically impact health on a wider scale. If we ignore these premises, we risk being ineffective in the long run. Marmot argued, "Why treat people and send them back to the conditions that made them sick?" We need to address the conditions that made them sick, and this means targeted work on the social determinants of health.

Vicky Hobart, Head of Health, Greater London Authority (GLA), explained the role of UK local administrations in promoting health, illustrating projects aimed at addressing specific population groups, such as children, promoted by the GLA. Several reflections on enabling factors were shared, with a significant focus on the impact of strong mandates aimed at the adoption of a HiAP approach. An example of a participatory strategy that led to wide consultation and involvement of stakeholders across the whole of London was of great interest to delegates.

Vesna-Kerstin Petric, Head of Division for Health Promotion and Prevention of Non-communicable Diseases, Ministry of Health, Republic of Slovenia, introduced her presentation with a comment on the title of the session, recalling how health

should not be minimised as an "asset", but must be seen as a fundamental human right, and therefore a value to defend. This is especially true if we consider the fact that finance ministries usually see health as an "expense". We need to put health as our first goal and to introduce indicators of social exclusion in order to assess the impact of health policies, she suggested. Petric also advocated that the health sector needs to be bold, by significantly investing in prevention and public health, and to be "brutally practical", by developing innovative tools for health professionals, and she introduced some examples of such projects in Slovenia. The introduction of "health profiles" (reports aimed at monitoring the health status of citizens) for each municipality incentivised local politicians to cooperate and contribute to improving the health outcomes of their local communities by comparing their municipality against others, for example. The creation of primary healthcare centres in Slovenian communities facilitated the linkage of actors including health professionals, NGOs and social services within the community, and enabled a particular focus on improving the health of the most vulnerable.

With the final intervention, Paul Lincoln, CEO, UK Health Forum, listed some current challenges in health policy development. As he explained, it is essential to introduce new strategic analytical tools, higher standards of proof, powerful modelling capabilities and encourage a deeper knowledge of the connections between epidemiological and the commercial/financial determinants of health.

### Breaking the cycle of ill-health and social disadvantage

It's clear that health professionals are aware of the impact of health not being considered an asset and the obvious correlations between deprivation and poor health. We as a public health community need to do more to bring this to the attention of policymakers and funders and break the vicious cycle of ill-health and social disadvantage across generations. Whether this is through ensuring that huge global employers and multinational corporations pay the taxes they should, or by giving municipalities more specific data about their populations so they can create specific guidelines to further health and well-being, one thing is clear: we need to burst our own bubble and remind those holding political power that a population's health should be prioritised.

Written by Nicholas Ray Morgan and Stefano Guicciardi





## Tackling uncertainties for rare diseases

### The use of RWE to improve access for patients

Organised by Shire



There are about 7000 rare diseases, defined as diseases that affect fewer than one in 2000 people. When it comes to achieving SDG3 (ensuring healthy lives and promoting wellbeing), patients with rare diseases are often overlooked. While an encouraging number of 174 orphan medicinal products (OMPs) obtained a license between 2000-2017, securing access remains a hurdle; in some countries less than 50% of OMPs are accessible. A lack of data can lead to late or no access to treatments.

Real world evidence (RWE) has the potential to address uncertainties surrounding evidence generation in rare diseases. This is important because “no country can claim to have achieved universal healthcare if it has not adequately and equitably met the needs of those with rare diseases” (Helen

Clark, Administrator, UNDP). Evidence gaps and uncertainties must be addressed and common solutions must be found.

The multi-stakeholder initiative TRUST4RD has developed a practical tool to provide guidance to decision-makers. This will be a living document, so the purpose of this workshop, moderated by John Bowis, Special Advisor to FIPRA, former MEP and UK MP, was to offer participants a chance to contribute and have their insights shape the document.

#### The TRUST4RD initiative explained

Vinciane Pirard, Senior Public Affairs Director, SANOFI Genzyme, introduced TRUST4RD, a multi-stakeholder initiative set up in 2017 to facilitate a shared understanding of the challenges faced by manufacturers, regulators, HTA, payers

and patient groups in the development and use of RWE to address uncertainties for the highly specialised treatments of rare diseases. The rationale behind this is that approaches agreed upon through a multi-stakeholder dialogue have the potential to increase trust and uptake of such evidence in healthcare decision-making. Concretely, a working paper has been produced containing 1) a comprehensive taxonomy of uncertainties relating to these challenges to delineate their nature and role in HTA and payer decision-making and 2) guidance to decision-makers on RWE generation options to address these uncertainties and to support understanding. The final paper will be ready at the end of 2018.

### Challenges: disparities, uncertainties, evidence generation

Heidrun Irschik-Hadjieff, Vice President, DACH Cluster, Shire, kicked off the discussion about challenges surrounding rare diseases by posing a question to delegates: can the healthcare system in your country generate relevant data to reduce uncertainties and support access to treatment for patients with rare diseases? Perhaps unsurprisingly, 60% of responders answered 'no' (20% said yes and 20% didn't know). From a patient perspective, according to Simone Boselli, Public Affairs Director, EURORDIS, there are stark and marked differences in and between countries when it comes to access to approved therapies for rare diseases and there are disparities in the assessment of evidence. It is hard to come to terms with these differences considering the current context

in which there are many exciting scientific developments. Patient participation in evidence generation, for example through PROMs (Patient Relevant Outcomes Measures) can help to improve the understanding of rare disease and the outcomes for patients and families, but this needs to be more widely taken-up by competent authorities.

Alexander Natz, Secretary General, EUCOPE, commented that from an industry perspective, some systems still see RWE as weaker evidence and think RCTs are far superior. There is a need for early dialogue to discuss payer needs, the type of data that should be generated, and if certain data cannot be generated at a certain point of time, there needs to be some flexibility. From the industry side it is very important to listen to the payers needs and consider what is possible in the context of the type of rare disease.

Liisa-Maria Voipio-Pulkki, CMO and Head of the Management Support Unit, Ministry of Social Affairs and Health, Finland, discussed the Finnish context, where there is a very unique spectrum of monogenic diseases and diagnosis and treatment of these is quite good. However, the Finns are facing new challenges, for example as the population becomes more diverse with migration the Finns are seeing the emergence of new conditions, such as PKU (Phenylketonuria) in newborns.

With low numbers of patients, sometimes as low as 50 or 60, it is hard to encourage industry interest in certain rare diseases.



European Reference Networks (ERNs) might be the answer, explained Maurizio Scarpa, Past Chairman ERN Coordinator Group, European Reference Networks. For the first time, specialists cooperate Europe-wide in certain fields, for example on metabolic disorders. This opens-up possibilities to generate data, speed-up diagnosis and crucially interest industry in the R&D of new medicines for rare disease patients.

Ruth Ladenstein, Professor of Paediatrics, St. Anna Kinderkrebsforschung e.V. and Head of the Clinical Trials Unit S<sup>2</sup>RP, CCRI, gave an Austrian perspective on rare diseases. Like other countries who have been slow to digitalise their systems, Austria is lagging behind in the implementation of a national plan for rare diseases, translating into a lack of oversight which is sorely needed to better understand the rare disease patient populations and reach out to them. Once there is better knowledge through population-based registries rather than disease specific registries then this is closer to RWE and where PROMS can come in, which is particularly important in the rare disease patient population. Quality of Life (QoL) and how medicines improve QoL really puts PROMS at the centre, Ladenstein stressed.

### **Bridging the gap between possibilities and reality: the role of stakeholders**

A positive note: we are going in the right direction, especially with ERNs. ERNs have impressive dimensions that can contribute to generating RWE. A lot of data that cannot be collected in RCTs can be obtained through ERNs, and contribute to unifying approval and the administration of drugs and creation of guidelines. This critical mass can really create the difference. We need to align initiatives and pick up on positive examples of RWE in negotiation agreements, for example the recent example of Spinal Muscular Atrophy (SMA) in Belgium and the Netherlands.

Interaction with industry is vital for funding research and for the application of therapies. Companies have an important role and collaboration is needed. Facilitating more scientific advice meetings would help. What is discussed there should be adhered to, and uncertainties should be outlined with clear end goals and time limits. To make good use of RWE, two things are needed: a digital infrastructure and legislation. Finland for example has 100% electronic health record coverage, so the infrastructure for RWE is there. But the question remains: how good, comprehensive, structured and trustworthy is the data?

These questions will be addressed during the Finnish EU Presidency, where RWE will be a theme.

If you want to go fast go alone, if you want to go far, go together. Heidrun Irschik-Hadjieff concluded the discussion by asserting that it is stakeholder collaboration that will allow the rare disease community to overcome challenges and reach goals. There is still a long way to go before healthcare systems can generate relevant data to reduce uncertainties and support access to treatment for patients with rare diseases. We have to get away from RCT-only thinking and see the potential of RWE and how to give it greater legitimacy, in the sense of who will fund, own and collect data. When it comes to tackling uncertainties, it's all about trust and communication, she emphasised: trust means we should establish an open dialogue that allows us to address these uncertainties, and we need to involve patients and to incentivise physicians to collect data. The TRUST4RD initiative and ERNs are valuable tools that can help us to reach our goals. There was a final nod to the Finnish Presidency of the EU in the second half of 2019, as the Finns seem to be paving the way in this area, so there is much that the rest of Europe can learn from them.

Written by Lilian van der Ven

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## The value of evidence in outcomes-based healthcare

Organised by IMI Big Data for Better Outcomes



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This session set out to explore the issues around using big data in order to gather information on disease treatments and the improvement of health outcomes. Speakers came from differing backgrounds, which set the scene for a lively debate between representatives of the pharmaceutical sector, public health sector, government and patient organisations.

### Public-private partnerships (PPPs) can maximise the potential of big data

In his introductory presentation, Shahid Hanif, Head of Health Data & Outcomes, Association of the British Pharmaceutical Industry, introduced the Big Data for Better Outcomes (BD4BO) initiative, with its mission to improve health outcomes and healthcare systems in Europe by maximising the potential of big data. The aim of the research programme is to develop platforms that integrate and analyse diverse data sets, focusing on outcomes that matter to patients and generating meaningful insights that will improve healthcare. Currently, there are four disease-specific projects in

place: Roadmap (Alzheimer's disease), HARMONY (hematologic diseases), BigData@Heart (cardiovascular diseases) and PIONEER (prostate cancer). Each of these projects approaches the issue from a slightly different angle in order to determine what is the best way of standardising and sharing data.

An important objective of the BD4BO initiative is to engage patients and their perspectives through the involvement of patient organisations. Lydia Makaroff, Director, European Cancer Patients Coalition, spoke about the value of patient-centred perspectives and seeing patients as co-researchers instead of subjects. As patients are not a homogeneous group, it is important to understand their diverse needs and preferences. The inclusion of patient organisations in the above-mentioned projects means that patients are consulted to ensure the materials produced are relevant and meaningful. Patients have unique knowledge and perspectives, and therefore play a key role as consortium members and contributors.

### Don't delay - start working with the available data

In the panel discussion, moderated by Richard Bergstrom, External Pharma Lead, SICPA SA, panellists from different sectors presented their experiences with big data. Miklos Szocska, Director, Health Services Management Training Centre, Semmelweis University and former Minister of Health for Hungary, shared his experience of saving lives and public money through adopting an agile approach towards working with big data. He described how he and his team started working with the available data immediately instead of waiting for new management systems to be in place. Through looking at the reasons behind scattered cancer patient pathways and conducting discussions with healthcare professionals, existing data and network analytics were used to increase the number of liver-metastases operations by 40% over 1.5 years. The team realised the use of data-mining techniques and network analytics could lead to financial savings, and subsequently managed to reduce financial expenditure in public procurement by introducing new business models that prevented pharmaceutical companies from monopolising the market. However, other panellists and the audience raised concerns about the quality of data, linking different data sources and the lack of standards, aspects which make working with data more difficult than presented, some argued.

### The importance of collaboration and trust

Ain Aaviksoo, CEO, Viveo Health and former Deputy Secretary General for E-services and Innovation, Estonian Ministry of Social Affairs, shared his experiences from and mutual trust for better outcomes in the field of big data. In Estonia, they acknowledged the need for a common information system in order to avoid inefficiencies. Nowadays, each Estonian citizen knows who is using their data and for what purposes. By using blockchain-based technology settings each citizen can monitor and give consent for using his or her personal data.

Trust is also very important for big data projects involving patients and companies. Nicola Bedlington, Secretary General, European Patients' Forum, described how in the Innovative Medicines Initiative, a PPP funding health research and innovation, a long process of dialogue and continuous patient engagement had to take place before patients were involved in a way that was satisfactory for them. Transparency, trust, ethical frameworks and a vision of genuine collaboration were all critical success factors in achieving this level of engagement and satisfaction. Based on her experience, patients are in general willing to share their data if it will help improve patient-related outcomes. However, patients are less willing to share their data for projects when companies are trying to monetise their data.

### What is the role for public health?

The pharmaceutical industry has a lot of resources to devote to maximising big data outcomes, but how about the public health sector? Petronille Bogaert, Scientific Coordinator, Sciensano, said that there is still much room for improvement in the public health sector. National public health institutes use a lot of data for monitoring and reporting, but it is not streamlined in the most efficient way. From the public health perspective, big data can be useful in setting up assessments of health information systems and population monitoring and reporting. However, government-funded institutes are often lacking capacity and are therefore lagging behind.

Clayton Hamilton, Unit Leader for E-health and Innovation, WHO Regional Office for Europe, described his organisation's special initiative to facilitate the digitalisation of health systems. The initiative focuses on ensuring a strong role for governments in data governance and looking at how the potential of big data can be used in order to achieve the highest levels of public health objectives.

### The road ahead

To conclude, in order for the PPP model to continue flourishing, collaboration with patients needs to be nurtured. Outcomes should not just be shelved at the end of a project, but continue to be used to benefit patients. Furthermore, it is very important that the public (health) sector takes a strong leadership role in setting standards for the production, quality and use of generated data in order to maximise the potential of big data and enable stakeholders to exercise control over their data. The examples discussed in this session show that with strong and transparent collaboration as well as a significant amount of trust, the vision of big data for better patient outcomes can become a reality.

Written by Daša Kokole and Rene Sluiter

Track IV  
No-one left behind







## Reaching the SDG targets on Health by 2030 Actions needed to end AIDS & TB and combat hepatitis in the EU

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



The epidemics of HIV/AIDS, tuberculosis (TB) and hepatitis have long represented complex challenges on the public health agenda – in Europe, and worldwide. Under the framework of the SDGs, new and ambitious targets are set for the global community, launching a dramatically accelerated fight against all three diseases: towards ending AIDS and Tuberculosis altogether, and significantly combating hepatitis.

In this session, organised and moderated by the ECDC, political delegates, representatives of civil society and members of European and UN agencies discussed challenges and possible solutions in achieving SDG target 3.3 for HIV/AIDS, TB and hepatitis in Europe.

Setting the scene, ECDC director Andrea Ammon highlighted that while several existing high-level policy documents address all three diseases – demonstrating political commitment to their elimination (see Box 1) - under current trend, Europe would fail to achieve the targets set out for TB and Hepatitis, while only EU/EEA countries would achieve those for HIV and AIDS. Vinay Saldanha, Regional Director for Eastern and Central Asia, UNAIDS, reminded the audience that the WHO European region is the only one where HIV infections and AIDS-related deaths are currently rising. With the bold and challenging targets of the SGDs, he explained, doing more of the same will not be enough.

<b>High-level policy targets for HIV/AIDS, TB and Hepatitis</b> <i>Adapted from Andrea Ammon's presentation</i>	
<b>HIV/AIDS</b>	<p><b>2030 target</b> 0 infections, 0 discrimination, 0 AIDS-related deaths</p> <p><b>2020 milestone</b> &lt; 500.000 infections AIDS-related deaths, 0 discrimination</p> <p><b>UNAIDS 90-90-90 target</b> 90% of HIV+ people diagnosed, 90% of those treated, 90% of those achieving viral suppression</p>
<b>TB</b>	<p><b>2030 target</b> 90% reduction of death, 80% reduction of incidence rate compared to 2015, 0 TB families facing catastrophic healthcare cost</p>
<b>Hepatitis</b>	<p><b>2030 target</b> 90% reduction of infections, 65% reduction in deaths compared to 2015</p> <p><b>2020 milestone:</b> 30% reduction of infections, 10% reduction in deaths compared to 2015</p>

### The data challenge

ECDC and UNAIDS representatives both highlighted the urgent need to improve data collection, monitoring and quality – a message reinforced by several members of the panel. Nikos Dedes, European AIDS Treatment Group, called for better data visibility and dissemination to influence key stakeholders. That concern was shared by panelist Francesco Negro, European Association for the Study of the Liver, who not only highlighted the lack of data to inform policy, but also the difficulty in ensuring policymakers take the existing data into account. Addressing a question from the audience concerning the spread of these epidemics among migrant populations, Andrew Amato, Head of Disease Programme HIV, STIs and Viral Hepatitis at the ECDC, confirmed that the emotional and political nature of the debate makes it hard for policymakers to focus on the science and the data.

### Reaching the hard-to-reach

The session emphasised significant challenges in reaching key affected populations such as migrants, men who have sex with men and the homeless, and panelists agreed that addressing these populations is indispensable to reaching

the 2030 targets. Reviewing the current response, Vinay Saldanha called on European countries not to limit themselves to reaching “low-hanging fruit”, but to aim for reaching underserved populations that are key to achieving the SDGs – a message reinforced by Nikos Dedes who explained that the targets themselves, expressed in percentages rather than absolute numbers, carry the risk of leaving people behind.

When exploring the reasons behind the difficulty in reaching these key populations, the panel highlighted structural, societal and political factors. Discussing the case of homeless people, Freek Spinnewijn explained that the common response to homelessness – shelters – are not only ill-equipped to identify and provide services to those infected, but often contribute to the spread of epidemics. Nikos Dedes highlighted the context of rising homophobia and xenophobia, with certain European politicians feeding the intolerance, as a barrier. He outlined how the criminalization of factors of vulnerability (e.g. migration or addiction) is preventing stakeholders from providing an integrated response to the diseases – and warned about the risk of increasing stigmatization of key affected populations. Promoting the provision of information about the key affected

populations while making sure that they are not blamed for spreading TB, HIV and HCV/HBV is instrumental, Dedes insisted – for example when it comes to migrants who arrive healthy to the EU and are infected with HIV in Europe as they become vulnerable and face multiple risks.

Panelists called for a response that goes beyond addressing the diseases alone - and towards addressing the underlying factors that make key affected populations disproportionately vulnerable to them. Talking about homelessness, Mr Spinnewijn suggested that the key focus should be on how to use every opportunity currently left unexploited. He insisted on the role of outreach activities for homeless people (e.g. street doctors), and the need to think about how to bring homeless people back into the general health care system, the clinics and ultimately, into society. Evidence shows that more stable and secure living conditions (housing, jobs) can decrease HIV incidence in the group, Spinnewijn explained. Ricardo Baptista Leite, Member of Parliament, Portugal, suggested to prioritise key affected populations, but also define clear population-wide goals. He called for political commitment and financial backing of goals that place clear focus on elimination of the discussed epidemics.

Public health should not be considered an “aside mission or charity”, Baptista Leite stressed.

### The Portuguese example: Eliminating HCV

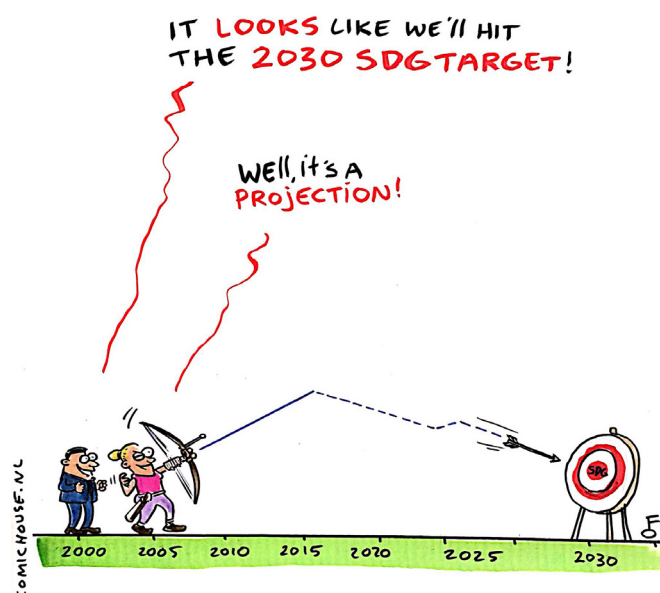
Ricardo Baptista Leite presented his country’s landscape

and described key steps which Portugal has taken in order to reach SDG 3.3. Initially driven by unsafe injection drug use, the HCV epidemic in Portugal correlated with the further spread of TB and HIV/AIDS. A dramatic increase in the number of drug users and failure to contain the situation through local policy created a dire situation. After decriminalizing drug use in 2000-2001, the number of new HIV and HCV cases started to decrease steadily while drug-related crimes dropped. Against opponents’ expectations, the new liberal drug policies did not lead to an increase of the number of people using drugs, and continue to contribute to effective HCV, HIV and TB prevention, especially in eliminating HCV amongst key affected populations.

Baptista Leite also introduced the UNITE network, a global platform of current and former policy makers raising awareness and advocating to end HIV/AIDS, viral hepatitis and other infectious diseases as public health threats by 2030. “I believe we have everything we need to end these diseases - what we need is political will”, Baptista Leite concluded.

### The civil society perspective: “We are the watchdogs”

Fanny Voitzwinkler, Global Health Advocates, addressed perspective and role of civil society for the inclusion of SDGs in the current EU political agenda. She described several recent campaigns, including release of a joint manifesto targeted at parliamentarians and advising on how to make SDGs operable





and include them in their agenda. Even though it is estimated that around 70% of EU citizens support increasing health care spending in the next EU budget, experts expect its actual share in the new budget to decrease by approximately 8% instead. Voitzwinkler deplored the lack of political will to address SDGs, and especially to include them into budget proposals – a reflection of current EU priorities. Voitzwinkler suggested that civil society should join forces, including different NGOs across different sectors. She called for the prioritisation of key affected population and the development of integrated joint plans with clear goals and allocated budgets to reach them.

Voitzwinkler also reported on the current TB epidemic in the EU, where approximately 1/3 of people with TB are not diagnosed and about 25% of people with MDR-TB are not being treated. Only 2/3 of all EU member states currently have integrated TB action plans, and those plans use different local approaches. Voitzwinkler suggested a Joint Roadmap on TB elimination in the EU with comprehensive guidelines for cooperation among multiple stakeholders, different EU policies and action plans. She insisted on the need to talk about global trans-border threats, highlighting the countless pushes made by civil society since 2010 to bring this approach to the centre of the current EU agenda.

### Coordinated action to address inequality

Andrea Ammon insisted that both the complex nature of the epidemics in question, and the nature of the SDG targets (i.e. with targets addressing diagnosis, treatment, health expenditure and discrimination) call for a multi-sectoral, societal and integrated response. In addition to civil society, the role of the private sector was mentioned by several speakers and most agreed that a proactive approach to involve private money should be considered.

Several comments from the audience echoed the importance of bringing social determinants onto the current political agenda, as well as developing integrated action plans to address them, since working with key affected populations without addressing their vulnerabilities and factors that create them cannot succeed.

### An urgent call to scale up efforts – 12 years left!

Participants agreed SDGs should be brought into high-level activism, and that political solidarity is key. At present, the health sector is not a top priority for political leaders, speakers

explained. Yet, according to Vinay Saldanha, we could learn from our past when the fight against HIV/AIDS was supported by numerous high-level political leaders. Fanny Voitzwinkler stressed that influencing the political agenda is something each citizen can contribute to, and we should not step aside from our responsibilities as each voice counts and makes a difference. “Let’s get political!”, Baptista Leite called.

A sense of urgency in the response to the three epidemics was palpable at the EHFG 2018. Europe will not progress enough to reach SDG 3.3 unless the current response is significantly scaled up. To do so, a change of mindset is needed. Panelists called for integrated approaches uniting key stakeholders across borders and sectors, with a priority given to reaching key affected populations by addressing inequalities and social determinants. Only political will and solidarity in the implementation of comprehensive plans with clearly defined goals will enable us to eliminate (not only control) HIV/AIDS and TB and combat Hepatitis by 2030.

Written by Anna Tokar and Elodie Besnier

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## Economic strategies for health equality

### Building bridges with business and economic development

Organised by The Health Foundation



How can we ensure that economic growth benefits all people? The impact of health inequalities on economic prosperity and vice-versa presented a hotly debated topic at the 21st European Health Forum Gastein. Economics and their inextricable link to health outcomes, social progress, fiscal responsibility and sustainable growth echoed through many of the discussions in Gastein in 2018 - and were at the centre of this lunch workshop.

#### Gaps in health and wealth – can we make growth inclusive?

Addressing health inequities has been a central aspect of the global health agenda over the past few years. As described by Fabrice Murtin, Senior Economist, OECD, “Inequalities are a major concern for policy makers as they are a major threat to the social good”.

Even in countries with stable outlooks for economic growth, its benefits and associated social progress are not reaching everyone equally, and the uneven distribution of wealth - and in consequence, health and well-being - have become major issues for policy makers. Participants acknowledged a pressing need to reduce entrenched income inequalities in OECD countries - and improve negative health outcomes associated

with disparity in social and economic standing, for example large discrepancies in longevity along educational status. Clear policy recommendations and frameworks for inclusive growth including a robust set of relevant indicators, Murtin stressed, can help to lead the way.

#### Embedding SDGs into business goals

Actions to tackle health inequalities and economic development can be mutually reinforcing, panellists asserted, and inclusive growth not only important for the economy, but good for business. The challenge for the health sector remains engaging its business counterparts in a dialogue on economic strategies for health equality and moving intersectoral collaboration forward.

Promoting the role of responsible business and the links between good work and good health is paramount - to realise this, SDGs should become a part of business goals and opportunities, in particular aiming to:

- Create **workplaces** that enable good health and wellbeing, e.g. mental health and wellbeing;
- Create **markets** that enable a healthy next generation, e.g. food and nutrition;

- Create societies that enable a **healthy planet** and healthy people, e.g. addressing air pollution;
- Create **supply chains** that enable the most **vulnerable workers and communities** to stay healthy and productive.

A multi-stakeholder effort is required to drive opportunities in this space, and mobilising businesses including their suppliers, employees – and crucially, consumers! – to lobby for public health is essential.

Exploring how business can drive sustainable change for the future of health and wellbeing is also at the heart of the UN Global Compact (UNGC), an international initiative for business sustainability. The UNGC aims to give globalisation a human face and to make it inclusive for all, explained Charlotte Ersbøll, Senior Advisor UNGC, and this includes connecting the dots between mental health, NCDs, planetary health and women's health.

Panel discussions highlighted how instruments of the OECD and UNGC work complementary in partnership: The OECD has developed an Inclusive Growth Framework and Dashboard which will provide updated analysis for governments to ensure the economy delivers for all citizens of their country. The shared goal remains to drive economic growth that creates opportunities for all and distributes the dividends of increased prosperity fairly across society.

### From corporate social responsibility to creating shared value

While there are several good practice examples of large corporations taking the lead on social responsibility in areas like migration or climate change, businesses are still not always aware of the impact they have on public health and social welfare, session participants asserted. "It is not enough to think about the employee-employer relationship", noted Emma Spencelayh, Senior Policy Advisor, The Health Foundation, "We need to consider how businesses interact with their community". Charlotte Ersbøll added that businesses "need to really listen to their communities and invite them in" if they want to understand social impact.

A paradigm shift from prescriptive corporate social responsibility (CSR) to creating shared value (CSV) was identified as paramount. Above all, a shift of mindset is needed in the perception of CSR from an act of philanthropy to a viable business strategy, which can create a win-win situation for organisations by enabling

them to perform their societal obligation whilst simultaneously performing their economic obligation.

Ultimately, a healthy population is essential for a thriving society and economy, and realising this potential requires coordinated action across the SDGs. The Goals, participants agreed, provide an opportunity and catalyst for health to bridge barriers and advance mutually beneficial policies, also with the private sector.

### Amplified impact: identifying new stakeholders and mechanisms

Impact can be increased if CSV is not only discussed with businesses, but also considered by shareholders and investors from pension funds to governments. Parliamentarians, too, can be considered as stakeholders – and act as agents of change.

Ultimately, public health stewardship could steer towards health goals in business also through regulation, much like mandating seatbelts for public health safety: even though adding seatbelts to a car may not be highest on the list of business priorities for car manufacturers, with the requirement to do so in place industry has found a way of complying and selling cars with seatbelts.

As for the public health experts, their task remains to communicate clearly why investing in health is money well spent – and build a compelling evidence base to prove it. Making the case convincingly requires urgent focus on continued development and monitoring of robust indicators in this area.

It is not easy to evaluate the impact of private business on health, panellists and participants agreed, but ultimately, this should be everybody's business. 'It starts', Charlotte Ersbøll concluded, 'by really understanding what your potential impacts are, and how you can be a force for good.'

Written by Fiona Dunne, Maaïke Droogers & Cara Pries

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## Digital and Access to Care for All

### Can digital innovation improve migrants' health?

Organised by MSD, the International Organization for Migration & the European Digital Therapeutics Partnership



Digital solutions continue to play a growing role in health, while equity of access to care remains a challenge throughout Europe – can the former help to address the latter? This session provided a platform for participants to consider the utilisation of digital innovations for promoting and upholding equity in health - and specifically, how such innovations can be applied in the context of migrant health.

The forum was chaired by Boris Azais, MSD, who outlined the



company's commitment to being involved in the conversation surrounding migration and health in Europe, following MSD's previous engagement with the topic of healthcare for underserved

groups at the European Health Forum Gastein 2017.

Soorej Puthooppambal of the World Health Organization Regional Office for Europe highlighted ways in which eHealth solutions have been deployed in challenging migration scenarios in both developed and developing contexts. With 10% of the European population made up of international migrants, he emphasised the growing importance of tools such as electronic health records and tele-psychiatry to facilitate access to healthcare for migrants, but he also noted the range of challenges to deployment of such tools, for example interoperability and data protection. He accented the importance of having comprehensive plans and clear objectives in place for using data while ensuring appropriate data protection, which is a significant challenge for all actors involved. There needs to be a common understanding on how to use data and for what purpose. Or as Puthooppambal put it, "it is not enough to have a car, you must know how to drive it"

#### Building trust, protecting privacy, realising potential

Michele Pastore of Samsung Electronics and DIGITAL EUROPE reinforced that we need to address many challenges when

trying to employ digital solutions to reduce inequalities - such as limited digital literacy. Denis Onyango of the African Advocacy Foundation presented the Foundation's work in facilitating HIV care for migrants in London by way of community champions. Apprehension about data protection in digital healthcare, he stressed, is a huge concern for users of services aimed at migrants in the UK. Developments like sharing of National Health Service patient data with the Home Office, as recommended by a recent Memorandum of Understanding, as well as the fact that migrants are often asked to provide access to their digital devices by authorities, have significantly contributed to decreasing levels of trust. But although data protection remains a concern for policymakers and service-users alike, the potential of digital solutions for allowing users to access their own data across borders is cause for hope and optimism, participants agreed - and may serve to shift power from health providers to their patients.



Kim Baden-Kristensen, Co-founder & CEO Brain+, showcased one example of how novel digital approaches can give patients proactive choices in treatment, recovery and prevention. Applications his company develops help patients with brain injury recover by engaging with long term and intense cognitive exercise regimes.

### Digital health on the European agenda

eHealth has been increasingly present on EU agendas as well. Razvan Teohari Vulcanescu, National Health Insurance House in Romania, as well as Marianne Takki, policy coordinator at DG SANTE, reaffirmed the inclusion of eHealth as a central tenet of future health policy. Considering Romania's upcoming EU Presidency, it was highlighted that eHealth tools need to be viewed as an asset and appropriately leveraged. To facilitate and oversee this, Romania has put in place a plan to establish a digital healthcare agency.

Participants were also offered insight into current digital solutions

from start-up founders hailing from across Europe. Diversification of funding and implementation of digital solutions was noted - participants remarked that these developments could help to enable future sustainability.

Field applications of eHealth in migration 'hotspots' have begun to reveal early benefits of deploying digital innovation within humanitarian settings. Previously, paper-based recording systems for migrant patients meant that patient information was often lost and completing records manually before uploading information to medical IT systems ultimately proved to be taxing and wasteful from the perspective of health professionals in Greece and other Mediterranean states receiving high numbers of migrants. The IOM's electronic patient health records - as part of the Re-Health programme - are designed to fill data gaps in migrants' individual health records and enable the sharing of health records between health workers across borders. In compliance with EU legislation, data protection using this particular tool is upheld, and there has been an assurance that no patient data will be shared with immigration departments, in contrast to the situation as described for the UK context previously.

### Can digital technology save the day for underserved communities?

Session participants shared their experience of using digital solutions and data as a good opportunity and perspective, but at the same time drew attention to challenges we must not lose sight of, such as data protection, literacy, ethical aspects and legislation.

The verdict for now seems to be that digital technologies are undoubtedly part of healthcare's future, and they are evolving along with evolving perspectives and challenges in public health - and that digital solutions can be used efficiently to help underserved populations, achieving concerted goals in healthcare, as long as we approach them with the respect and attention to all aspects and implications that is required.

Written by Liene Skuja and Christy Braham

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## Vaccines for all - Leaving no-one behind

### A life-course approach to vaccination

Organised by MSD and The Coalition for Life-course Immunisation



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Vaccinations have long served as a cornerstone among public health interventions and can aid to reach targets on several SDGs. However, despite their potential as a cost-effective and powerful public health tool, the benefits of vaccination are not always fully realised and implementation remains inconsistent, argued participants of this session on life-course vaccination at the EHFG 2018.

The session aimed to explore the merits of a life-course approach to vaccination – that is, the aim to vaccinate people at all stages of their life, depending on health status, risk factors, lifestyle and occupation, instead of focusing vaccination programmes primarily on one demographic such as young children. Panellists and audience highlighted some of the real-world challenges of implementing life-course vaccination and discussed tangible actions to move this concept into practice, and ultimately improve vaccination rates in Europe.

Experts' keynote presentations as well as lightning talks on

successful case studies tackling different facets of immunisation set the scene for discussion during the workshop phase, where groups of participants worked with the case study presenters to discuss transferable lessons and identify possible barriers to implementing these initiatives in their own settings.

#### The role of the European Commission

John Ryan, Director, Public health, country knowledge and crisis management, DG SANTE, EC, described the work the EC is doing to support Member States in reaching the SDGs with regard to implementing vaccination programmes and maintaining vaccination coverage. He highlighted the socioeconomic benefits of a life-course approach to vaccination, asserting that "Vaccination may save societies approximately ten times more than the original cost".

A recent initiative taken by the EC is the Proposal for a Council Recommendation and Commission Communication to strengthen EU cooperation on vaccine preventable diseases, whose implementation is supported by the EU Joint Action on



Vaccination that started in September 2018.

Ryan expressed concerns over the recent change in approach to vaccine preventable diseases of several large Member States. He called for reflection on how this could impact the overall protection of the entire European population and urged to consider the issue at the political level, and gauge how a consensus could be reached on the importance of each Member State signing up to an effective vaccination policy. Karin Kadenbach, Member of the European Parliament, echoed these same concerns.

### Life-course vaccination - helping to achieve the SDGs

Martin Taylor, General Secretary of the CLCI, provided insight into the meaning of a life-course approach to vaccination (Figure 1). Vaccination is not just for children, but beneficial at all stages of life, Taylor asserted – but not everyone who could benefit currently receives the vaccination they need. The ethos of the SDGs – leave no one behind – also emphasises that we need to work harder to reach vulnerable and hard-to-reach groups as we implement a life-course approach to vaccination, which could play a key role in achieving 14 out of 17 Goals.

**Case study 1:** Emilie Karafillakis, Research Fellow, Vaccine Confidence Project, London School of Hygiene & Tropical Medicine, described 3 key components of a wider comprehensive strategy implemented in Denmark to bring about behaviour change and reverse the drop in HPV vaccine uptake due to rumours of alleged side-effects that spread from Japan into Europe. The strategy included: 1) Engaging all relevant people in a community such as parents, adolescents, grandparents and friends, and involving them in the development of a communication strategy by actively soliciting their preferences and opinions; 2) Better utilisation of social media, as this is where concerns and rumours are usually spread and best counteracted and addressed; 3) Putting faces to statistics with individual interviews, photos, videos – as Karafillakis reminded us, ‘People overall react much more to emotional stories – stories that they can relate to from other mothers, other adolescents – than to cold scientific facts’.

**Case study 2:** Nicola Bedlington, European Patients’ Forum (EPF), focused on vaccination literacy in Europe’s patients. She highlighted the vulnerability of patients with underlying chronic health conditions to communicable diseases, and the importance of herd immunity to protect those who cannot be

vaccinated. Recent surveys conducted amongst the patient community reveal a high degree of vaccine hesitancy and a lack of accessible information. Bedlington emphasised the need to improve vaccination literacy among patients through the provision of more accessible, consistent, evidence-based information that is specifically tailored to patient groups. She described how EPF are currently developing targeted resources for patient groups in Romania and will be organising a workshop with the Coalition of Organisations of Patients with Chronic Diseases in Romania to work collaboratively towards improving patient access to vaccination – and ultimately make vaccination an integral part of the patients’ care pathway everywhere.

**Case-study 3:** Ramazan Salman, Managing Director, Ethno-medizinisches Zentrum, described experiences and lessons from the MiMi vaccination initiative in Germany targeting migrant communities with the aim of improving awareness and knowledge on vaccination and increasing vaccination coverage. A multi-sectoral, collaborative approach was used. Cultural mediators were trained on vaccination and in turn organised information events for thousands of migrants and refugees all over Germany. Comprehensive information guides in 16 different languages were distributed to participants. One of the main factors of success, Salman highlighted, was that information was delivered to migrants in their own language and by people from their cultural backgrounds.

**Case-study 4:** Jan De Belie, Professional Affairs Advisor, Pharmaceutical Group of the EU, focused on the role of healthcare professionals as vaccination advocates and how they can work together in a complementary way. He stressed that different population groups have different access points to the healthcare system and this needs to be taken into consideration in our efforts to reach everyone. In the case of the Irish influenza in 2011, community pharmacists in Ireland were enabled to deliver vaccinations in community pharmacies which led to a 29% increase in the number of flu vaccines administered. Both community pharmacists and general practitioners contributed to this increase, demonstrating, as De Belie highlighted, the complementary roles that healthcare professionals can play when engaged in an integrated way.

### Workshop outcomes: Barriers, enablers & success indicators

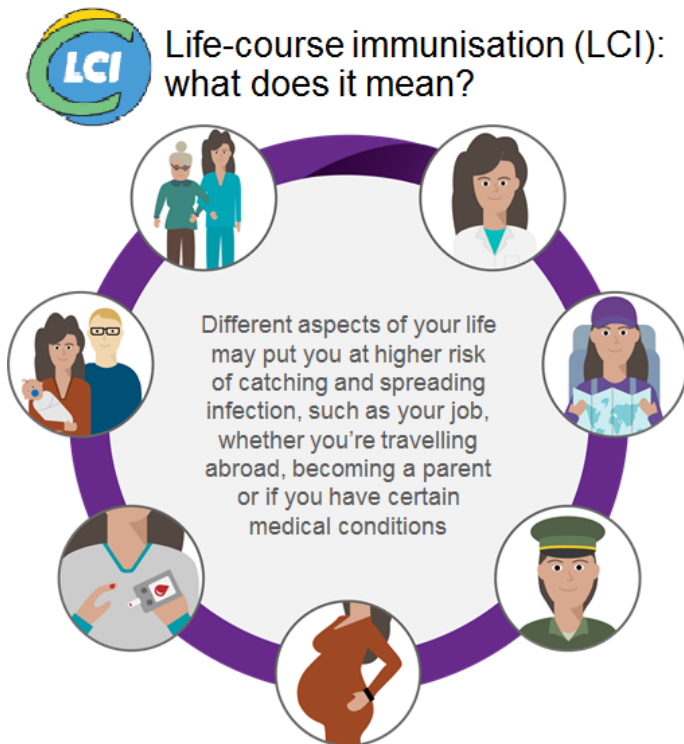


Figure 1 - The life-course approach to immunisation (*The Health Policy Partnership, 2018, as presented by Malcolm Taylor, 5th October 2018*).

- Engaging key opinion leaders, influencers and celebrities in communication strategies to make them more appealing to people.
- Making vaccination points more accessible e.g. at the workplace.
- Working with young groups since they have fresh ideas, are capable of conveying strong messages and know how to use social media.
- Provision of training to journalists to reduce the risk of spreading misinformation.
- Increasing migrants' trust in the healthcare system and access to vaccination through trained cultural mediators and multi-lingual information materials.
- Greater involvement of healthcare professionals since they are well placed to be vaccine advocates, including adequate information and training for healthcare professionals to ensure that consistent messages are given to patients/clients.
- Utilisation of social media to convey evidence-based information, address concerns and misinformation.
- Adopting a multisectoral approach and engaging all relevant stakeholders.

#### Barriers:

- Lack of government support.
- Insufficient knowledge and training among healthcare professionals in using social media/different communication strategies with different target groups.
- Insufficient human resources to manage social media which includes monitoring content, answering queries and concerns, and developing information materials.
- High out-of-pocket costs to buy vaccines where these are not given for free.
- Vaccine shortages and disinvestment by industry in vaccination.
- Provision of inconsistent information by different healthcare professionals, in different settings and on social media.
- Migrant communities have unique access barriers due to language, culture, status and physical location. Negative political views on migrants influence the climate making access more difficult.

#### Enablers:

- Integrating vaccination as part of a healthy life approach.
- Using real-life stories that the target audience can relate to.

#### Measures of success:

- Vaccine uptake and coverage, especially in hard-to-reach groups.
- Vaccine confidence (e.g. using the Vaccine Confidence Index developed by the Vaccine Confidence Project).
- Monitoring media for positive and negative content.
- Data analytics in relation to social networks and media presence.
- Feedback from patients to assess trust levels.
- Number of immunisation days.

When it comes to tackling the identified challenges, participants agreed that we cannot succeed without involvement of all stakeholders - politicians and policy makers, healthcare professionals, civil society, patient groups, business. And, as Malcolm Taylor reminded everyone, we need to keep sharing good and bad experiences - after all "Nobody has a monopoly on wisdom, we can all learn from each other".

Written by Annalise Borg



## Sustainable strategies for addressing health inequalities

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Organised by European Health Forum Gastein and EuroHealthNet



This session, moderated by Louise Boyle, Programme Advisor, EHFG, and Caroline Costongs, Director, EuroHealthNet, focused on health inequalities, which continue to persist and grow to an unacceptable degree between regions, communities, countries and different populations across Europe. Health inequalities are unfair and unjust, and they are also costly to society. But above all, this is a human rights issue – the right of everyone to the highest attainable standard of physical and mental health. High levels of social inequalities lead to stress, insecurity and feelings of powerlessness, so to ensure high levels of health and wellbeing as well as political and economic stability in Europe, there is a pressing need to address and prevent ill health and reduce inequalities within and between MS. The aim of this session was to discuss how to build healthier communities and tackle health inequalities in a sustainable and effective manner.

Sir Michael Marmot, Director, Institute of Health Equity, University College London, began the session by introducing the three dimensions of the INHERIT project (living, moving and consuming)

and presenting selected examples of health inequalities related to green space and energy efficient housing. Discussing the latter, Marmot reflected on excess winter mortality in the UK, stating that based on an average of the last five winters, nearly ten thousand people annually died from factors attributable to living in a cold home. Excess winter mortality in the UK is worse than in Sweden and Finland, where they have harsher winters than the UK. Data shows winter mortality affects poor people more than rich, following the social gradient, therefore some countries do a much better job of addressing the issue of poor-quality housing than others. Marmot also shared an interesting personal account of using the metro in Paris, where he was surprised by a free metro ride because of high pollution levels in the city. Subway transport is indeed free of charge in Paris when air pollution exceeds set levels – a sensible policy which sends a very strong message to other European metropolitan areas.

Martin Schenk-Mair, Deputy Director on Social Policy, Diakonie, Austria brought to bear the experiences and perspectives of



people from the lowest socioeconomic groups, those who live on the breadline and experience cumulative inequalities. For them, the idea of a good life is a combination of accessible public transport, decent wages, warm housing, a good job and also small comforts such as music and books. Schenk-Mair shared a touching story of a young woman and a small juice carton. As a child, all this woman's classmates in school had juice cartons, but every time she asked her mother to buy one, the answer was that it was too expensive. When she grew up and earned her first salary, she went to the supermarket and finally bought a juice carton. For her being able to purchase this carton represented a form of attainment and of societal participation. If we want to be efficient in fighting health inequalities, we have to acknowledge the emotional dimensions of social inequalities as well, emphasised Schenk-Mair. He introduced the expression "toxic cocktail" which refers to living in extreme poverty and comprises high demand, low control and low recognition. One of his recommendations for health systems, from a pro-poor perspective, was to offer psychosocial support services to people from these lowest socio-economic groups, as they are very often feeling ashamed and isolated in their daily lives.

Yvonne Doyle, Regional Director London, Public Health England (PHE), and Health Advisor to London Mayor Sadiq Khan, spoke about her work in the capital and activities at the city level with politicians. There is still a huge problem with inequalities in the UK despite 70 years of national health programmes and the introduction of many promising policies. Doyle echoed Marmot's words, saying that she was most enthused about furthering work on giving every child the best start in life, as that is where evidence is strongest that a major difference can be made in tackling health inequalities with relatively simple interventions. Recognising that a multi-faceted response was required to tackle complex problems, Doyle and her colleagues identified five dimensions where they wanted to see changes (healthy children, healthy minds, healthy places, healthy communities and healthy habits). Doyle then approached the London deputy mayors of areas including housing, transport, spatial development, culture, and environment, and presented them with evidence-based approaches from their areas that could contribute to work on health and inequalities. For example, the environment and transport mayors are working on healthy streets; strategies to tackle fast food and gambling shops are being introduced in the area of planning and spatial development; in the culture portfolio there is work afoot on how to make London more dementia-friendly, smarter and more accessible to older people. These

strategies are grounded in a partnership approach that has also taken the experience of other cities such as Amsterdam, Paris and New York into account. Finally, Doyle highlighted some key learnings. She called for an end to learned helplessness and to the idea that imposing behaviour change on people works. Social movements, particularly those supported by technology and digital solutions, can really empower and accelerate progress, she advocated. Finally she explained that the public health community might often be challenged about the specifics of the evidence behind some of the interventions that are proposed, highlighting the case of advertising of fast food on the London Underground, where PHE is being challenged on which foods and which formulations are responsible for obesity. But it is vital for public health activists to be in this space and respond without alienating partners and supporters from testing other measures in future, she stressed: the question should simply be whether some of these measures might help vulnerable people: sometimes it's a case of trial and error.

Caroline Costongs, Director, EuroHealthNet, is leading the INHERIT project, a Horizon 2020 funded project which links sustainable development and health inequalities. The starting point of the project is that we are not living sustainably. Overconsumption in general, increased exposure to air and noise pollution, high density of fast food outlets, poor housing conditions, insufficient green areas - all are determinants of health and contribute to health inequalities. As mentioned by other panellists, people in lower socioeconomic groups experience cumulative inequalities and become locked in situations that consequently lead to fewer coping resources and prevent certain vulnerable populations from escaping from the downward spiral of social inequalities. INHERIT looks at the different drivers (economic, political, and technological) and how they influence the environment and health. Three different examples from the project were selected for small group discussions. Delegates were asked whether they thought the selected good practices would contribute to reducing health inequalities (and if so how to scale them up, or if not how to ensure they don't contribute to widening inequalities), and how to ensure that both technological and social innovations will also benefit those from lower socioeconomic groups.

Karin Schindler, Head of Department for Mother, Child and Gender Health and Nutrition, Federal Ministry of Labour, Social Affairs, Health and Consumer Protection, Austria highlighted that food systems are very much connected to health. Stand-

alone solutions are ineffective and unsustainable – instead we have to find different solutions at a systemic level where those who are acting in the food system can find co-benefits in collaborating to promote a healthy food environment. Schindler underlined that we all have a choice but not everybody has an easy choice, bringing the perspective back to those from lower socioeconomic groups who might be time and resource poor, holding down multiple jobs, in caring roles and earning low wages. Changing the environmental context in which we make choices is, in Schindler's opinion, the correct route to achieve positive changes in food systems and nutrition.

Dirk Van Den Steen, Policy Officer, DG SANTE, EC, gave a presentation focused on relevant policy developments at the EU level, in particular the European Pillar of Social Rights (EPSR), how this interacts with the European Semester (ES) and what this means for health systems and health inequalities. The EPSR was proclaimed by MS, the EP and the EC on November 17, 2017 in Gothenburg. There are 20 principles and rights assessed through three dimensions: equal opportunities and access to the labour market, fair working conditions and adequate and sustainable social protection, which also includes health. Specifically, Principle 16 of the EPSR states: "Everyone has the right to timely access to affordable, preventive and curative health care of good quality." The EPSR is practically integrated into ES country-specific reports through a summary paragraph in the Executive Summary regarding MS performance in terms of the Social Scoreboard that supports the EPSR. There is also a box that gives more statistical indicators on MS performance in three areas: unmet need for healthcare; share of out of pocket spending at household level and healthy life expectancy, as well as highlighting relevant good practice examples and particular challenges in terms of the EPSR and Scoreboard. With the instrument of the EPSR we therefore have an argument for further strengthening the social dimension of the ES and providing strong leverage for change. Van den Steen also added that the EC has announced that for the next Multi-annual Financial Framework (MFF), they will be linking the European Social Fund Plus (ESF+) and Cohesion and Structural Funds more closely to the ES.

Giuseppe Costa, Professor of Public Health, Turin University Medical School, Chair of the San Luigi Hospital Epidemiology Unit and of the Regional Epidemiology Unit, Italy, stated that the mortality rate of lower educated people now is the same as the mortality rate of more highly educated people 40 years ago.

Costa highlighted a wide heterogeneity in the development of policies and interventions to reduce health inequalities in Europe, from countries with comprehensive cross-government strategies targeting the social gradient of health inequalities that are evaluating their work well, to those doing nothing at all or simply relying on population-based health interventions with little evaluation of their impact. He presented the Joint Action Health Equity Europe (JAHEE), launched in 2017 with €2.5 million EUR of EU co-funding and designed to promote better cooperation (JOINT) and engender concrete actions (ACTION) in 25 countries to tackle health inequalities. This project has five thematic work packages (monitoring and governance, healthy living, environment, migration and access to health). Health inequalities still represent a large reservoir of health benefits that could be gained in every European country, he emphasised.

By the end of the session all speakers agreed that identifying the best practices that are sustainable and effective in tackling health inequalities is a challenging task constrained by the macroeconomic barriers of the modern world and the fact that we are dealing with trying to make changes to complex, real-world systems. To be effective in our actions, we have to know what works, how it works, can it be measured and compared to other interventions and is it transferable and scalable? Sir Michael Marmot concluded the session by saying that we can't forget the underlying causes of health inequalities – the organisation of our societies that precipitates the unequal distribution of power, money and resources. He made a suggestion based on the work of fellow colleagues at UCL: what about introducing universal basic services as an alternative to universal basic income? We accept universal basic services when it comes to healthcare and education, but what if there were universal basic services additionally for food and nutrition, transport and communications? It is possible to organise our societies in different ways to ensure that everyone has access to the minimum needed to live comfortably. He finished by highlighting that we can recognise that improving health for those worst-off is a major societal achievement. But if inequalities are increasing between population groups then that is a major challenge if we want to create fairer societies.

Written by Zeljka Stamenkovic and Louise Boyle



## Long term access to vaccination across Europe How to improve our vaccine ecosystem?

Organised by Sanofi



The fight against vaccine-preventable diseases (VPDs) plays an important role in ensuring population health – and sustainable access to vaccination remains a crucial issue for healthcare systems. In recent years, dropping vaccination rates have given rise to concern throughout Europe and there have been notable outbreaks of VPDs such as measles. While public health advocates agree that this should not be happening, the question remains: How can we effectively reverse this trend and ensure a functioning vaccine ecosystem? In this workshop, participants aimed to identify forward-looking solutions and steps towards making sustainable access a reality across Europe.

### Improving coverage: procurement, legislation and communication

An Baeyens, Legal and Policy Officer, DG GROWTH, European Commission, gave an overview of public procurement processes, and highlighted how smart examples of public procurement can lead to drastic improvements in health outcomes.

Procurement directives apply to all public authorities, she explained, and public procurement aims at not only cost reduction but best value for money, under principles of transparency and non-discrimination. As a strategic tool, public procurement can also promote patient safety because it leaves room for innovation, Bayens asserted. She highlighted real-life examples of procurement for health products like cataract lenses, where combination of the supply contract with a procurement of services to help identify best application of different products for specific patient groups led to a drastic decrease in side effects and complications, together with a modest reduction in cost.

For vaccines and other areas 'a lot is possible' when employing procurement smartly, Bayens concluded – but she also stressed that it remains underused as a tool due to lacking expertise by health actors. There is a clear need for public procurement experts in the health sector to make use of untapped potential in available but unawarded public procurement contracts, and to use procurement mechanisms

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to greatest effect to benefit people and patients.

Tim Wilsdon, Vice-President, Charles River Associates (CRA), elaborated on the relationship between purchasing methods for vaccines and protection against VPDs. In a recent study conducted by CRA, purchasing methods were stratified from price-based to value-based approaches and compared across several EU Member States - and a strong correlation between sustainable purchasing models and vaccination coverage emerged. Strictly price-based tenders reduce choice and provision of value-added services, and while they can effect a price reduction for vaccines, they do not lead to sustainability in supply. Moving toward more sustainable purchasing methods and value-inclusive tender criteria, Wilsdon concluded, brings significant benefits in safeguarding public health - better vaccination coverage, supply sustainability and incentives to invest.

According to Carlo Signorelli, Professor of Public Health, University of Parma & Vita-Salute San Raffaele, there has been a worrying decline in vaccine coverage in Italy amid sceptic attitudes to vaccination, and increased prevalence of VPDs such as measles as a consequence. In 2017, Italy implemented a new law on vaccination: the number of mandatory vaccines was increased, with certificates of vaccination necessary for pre-school admittance and fines imposed for non-compliance from primary school onwards. Six months after passing the new law, vaccine coverage for measles increased by 4.4%, the highest spike in coverage after a previous steady decline since 2013. It seems that legislative means were effective - but the debate surrounding mandatory vaccination remains a matter of controversy.

Radu Ganescu, President, National Coalition of organisations for patients with chronic conditions of Romania, affirmed that the situation in Romania is similar to that in Italy. Vaccinations have been made obligatory by law for children in particular settings including nurseries and primary schools, and penalties are associated with non-compliance, but the debate about ethical justification is enormous. And although vaccinations are mandatory, a significant problem is presented by shortages. It is crucial, Ganescu stressed, to emphasise the right to access:

Everyone should have access, shortages should be addressed and reliable information needs to be readily available.

Debate around vaccines, however, is carried on also on social media, where individual accounts of people sharing personal opinion or experience are often deemed more trustworthy than results of peer-reviewed studies. The challenge for public health advocates remains to teach media literacy and identify best avenues to build trust. Is it better to get people to understand the benefits of vaccines rather than force them to be vaccinated through legislation? How can we convince people of the risks of diseases they often assume they will not be personally affected by? More research is urgently needed in the realm of effective communications, as well as to evaluate long-term benefits and drawbacks of mandatory vaccinations throughout the European region.

### **The way forward: collaboration!**

There is clear need to enhance vaccination coverage and fight VPDs through integrated approaches with all stakeholders, participants agreed.

Ensuring a sustainable supply of vaccines remains essential to achieving equitable access. Used smartly, public procurement is a strategic tool with the potential to effect change in this regard, if we can raise the number of public procurement experts in health. Moving toward more sustainable and value-based vaccine purchasing methods can translate into better outcomes for people - but also into higher savings for buyers and sellers in the long run.

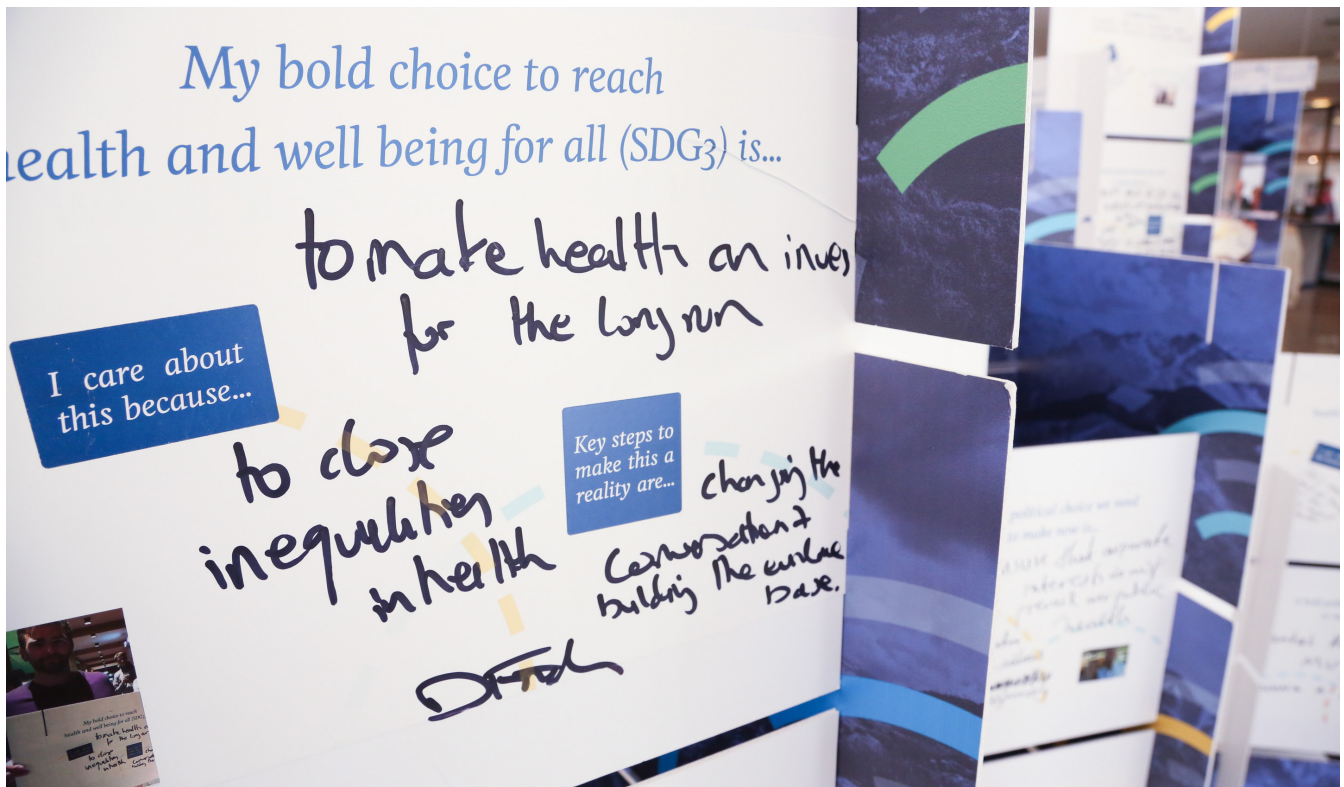
On the other hand, it is important to increase awareness of VPDs and secure trust in vaccine benefits, and communications present a crucial tool in this. Policies that make vaccination obligatory may provide one effective avenue to increase coverage - but debates around the ethical implications remain highly controversial. A lasting goal for Europe's future must be to move toward informed people, willing to take advantage of vaccination - while keeping vaccine safety, access and availability high on the agenda.

Written by Pia Blomqvist and Cara Pries

# Policy Outcomes and Recommendations







## Policy Recommendations from the EHFG 2018 Written by members of the Young Forum Gastein

### Changing the Narrative: Bold political recommendations for achieving health within the 2030 Agenda for Sustainable Development

#### 1. What is needed?

'Enthusiastic people working for the same vision. Thinking big!'  
(Riina Sikkut, Minister of Health and Labour, Estonia)

The policy environment today is more complex and challenging than ever. We are facing both new and old challenges and opportunities in public health. The challenges range from increased communicable and non-communicable disease rates, ageing populations, social inequalities and health inequities, to environmental pressures, tight public budgets, health workforce shortages and skill gaps. These issues add further pressure to healthcare that is already operating in a resource-limited context.

The Sustainable Development Goals (SDGs) provide an opportunity to address important aspects of the sustainable future of society, economy and the environment. In particular, SDG3 (Good Health and Well-being) focuses on ensuring healthy lives and promoting the well-being of all ages in order

to guarantee sustainable development. Health is, however, an essential component of other SDGs, with many of them having health-related targets, such as SDG2 on hunger, SDG6 on clean water and sanitation, SDG7 on clean energy, SDGs related to climate change, and targets related to violence and discrimination.

*"Investment in health is crucial!" (Zsuzsanna Jakab, WHO Euro Regional Director)*

Current investment strategies have proven to be unsustainable, burdening current and future generations. We therefore need to change the way we invest, in order to create healthy populations and respond to challenges. Governments need to work in collaboration with different sectors to create healthy policies targeting the wider determinants of health, thereby recognising the multi-dimensionality of public health related challenges. Most importantly, we need to cast aside the narrative of 'health as a cost'.



*“We should all read the Financial Times as much as we read The Lancet!” (Ilona Kickbusch, Director of the Global Health Centre, Graduate Institute Geneva)*

Besides changing the “health as a cost” narrative, in order to turn the tide, we need intersectoral collaboration. It is now fundamental to raise healthcare higher on the economic and financial agenda of governments. This can be done by working peer to peer with other sectors towards a balance between economy and finance, and health and well-being. Furthermore, we need to recognise that investment in health now - especially in preventative measures - will result in future benefits. Health systems will then be able to work organically in order to fully integrate the SDGs into their objectives and activities, and move towards equitable access to high quality, efficient healthcare for all.

## 2. How could different stakeholders contribute to changing the narrative for health?

### Recommendations for Supranational Organisations

- Keep health high on the agenda of the EC by maintaining a dedicated Directorate General for health that works to integrate health across all policy areas. Create a new role - a Vice-President for Health.
- Elaborate the SDGs and promote the highest level of political discussions as a framework and a tool for countries to create sustainable health systems.
- Effectively implement the European Pillar of Social Rights - we have the opportunity to use this instrument to further strengthen the social dimension of the European Semester and provide strong leverage for change.
- Consider holding joint EPSCO Council meetings between health and social affairs ministers. They are responsible for overlapping issues which would deserve a pragmatic, joint approach to harvest synergies.
- Appoint a Chief Economist at the World Health Organization who can actively engage in and shape financial discussions.

### Recommendations for Governments:

- Exhibit strong leadership and governance through dialogue with different stakeholders and civil society to push a new narrative on investing in health: health as an investment, not

a cost. Develop mandates, structures and tools for health leaders to push the new narrative forward.

- Tackle poverty and income inequality as a main barrier for healthier populations. Ensure fiscal sustainability to improve productivity. Promote macroeconomic stability and an economy of wellbeing (see Finnish Presidency of the Council of the EU, July-December 2019).
- Establish a strategic multi-sectoral framework for SDGs at governmental level followed by a defined implementation agenda and practical mechanisms.
- Explore simultaneous policy development processes to enable a Health in All Policies approach and thorough Health Impact Assessment in policymaking, promoting and sharing responsibility for health across sectors, including at ministerial level.
- Support and push the private sector to be more accountable for the health impact of their activities. Collaborate with the private and not-for-profit sector on social impact investment projects.
- Promote the efficient use of best practices through the thoughtful transfer of innovation between different health systems.
- Consider introducing a policy of universal basic services as an alternative to a universal basic income – expanding on access to healthcare and education to include public transportation, communications and nutrition.

### Recommendations for Science and Academia:

- Engage in projections and forecasts that analyse the long-term effects of investing in healthcare – make the economic case for investing in health and how well-funded health systems can provide positive social and economic values for society.
- Establish a dialogue with policymakers, industry and civil society to ensure that views and key issues from stakeholders are addressed by studies and through data collection.
- Implement innovative research tackling major gaps in knowledge on the impact of health on social and economic outcomes: educational development, economic outcomes, socio-economic outcomes. Improve the evidence-base on short-, medium- and long-term benefits of reducing health inequities.
- Study new health economic models that better reflect the model of Health in All Policies and all policies for health.
- Strengthen health researchers and professionals’

understanding of the economy, financial flows and commercial determinants of health through reviewing the curricula of health-related secondary and tertiary education (medicine, public health, epidemiology, health economics).

- Develop more “social” business schools, to equip people with the knowledge and tools to act socially in every facet of their lives.

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### Recommendations for the Private Sector:

- Maximise opportunities to ensure that the market economy considers and positively influences the health of citizens, with private sector organisations evaluating the impact of their activities on healthcare and the healthy lives of citizens.
- Healthy and ethical investments for a healthy society: lobby businesses and raise wider awareness of divestment strategies to limit private investments in health-hazard related industries (e.g. the tobacco industry).
- Prioritise employment and wellbeing through long-term policies and actions, focused on ensuring inclusive growth and social responsibility.
- Work towards fair and reasonable profit and premiums: from Corporate Social Responsibility to Corporate Social Value.
- Scale up social impact investing: promote awareness of social entrepreneurship within society and government and find innovative solutions for access to capital.
- Collaborate with the public sector, civil society and academia to ensure more efficient use of resources: innovation should be aligned with societal needs to avoid waste of R&D funding.
- Take forward the concept of innovative medicine (not medicines) – an integrated approach to healthcare delivery.

### Recommendations for Civil Society:

- Support a new narrative for investing in health through targeted multi-stakeholder collaboration and taking an intersectoral approach to health.
- Engage in active coalition-building to lobby authorities on Health in All Policies and the new narratives.
- Continue to actively challenge industries selling products responsible for ill-health.
- Continue to actively challenge national and supranational policies that negatively impact health.

## 3. Conclusions and way forward

To reach the SDG goals, we need to rethink the way the public health sector is operating, addressing the multifaceted nature of challenges with a whole-of-government and whole-of-society approach. The way forward is to stop seeing health care as a closed-in system, and start perceiving it as an essential part of the bigger system in which we all coexist.

*Our vision: To create a sustainable, prosperous and healthy future for all in the European Region*

The SDGs represent a paradigm shift, and an opportunity to shape a powerful discourse integrating the healthcare sector with other societal frameworks. This can be achieved through the following overall recommendations:

- Change the narrative for health: further advance the understanding of health as an asset for the economy, employment and the whole of society - “Health as investment, not a cost”
- Break the silos: only through multi-stakeholder and intersectoral collaboration will it be possible to increase resources for health, place healthcare in all policies and have all policies working for health.
- Health as a core component of sustainable development: scale up a framework which can also be used by other sectors to set specific objectives, measures or indicators which support an integrated approach to implementing the three pillars of sustainable development: economic, environmental and social (informally known as people, planet and profits).

Written by Damiët Onderstal and Damir Ivanković, with the support of Michele Calabro; Ana Stielke; Kadri Miard; Neli Garbuzanova; Julia Köppen and Ana Raquel Nunes

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