

# 18th European Health Forum GASTEIN

30th September to 2nd October 2015

## CONFERENCE REPORT 2015

### SECURING HEALTH IN EUROPE

Balancing priorities, sharing responsibilities

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Published online 16.03.2016

# abbreviations

AMR	antimicrobial resistance
BMI	body mass index
DG CONNECT	Directorate-General for Communications Networks, Content & Technology
DG DEVCO	Directorate-General for International Cooperation and Development
DG ECFIN	Directorate-General for Economic and Financial Affairs
DG EMPL	Directorate-General for Employment, Social Affairs and Inclusion
DG RTD	Directorate-General for Research and Innovation
DG SANTE	Directorate-General for Health and Food Safety
EC	European Commission
ECDC	European Centre for Disease Prevention and Control
EMA	European Medicines Agency
EU	European Union
GP	general practitioner
HiAP	health in all policies
HCPs	healthcare professionals
HTA	health technology assessment
IHR	International Health Regulations
ICT	information and communication technology
IT	information technology
JRC	Joint Research Centre
MAPPs	Medicine adaptive pathways to patients
MEP	Member of the European Parliament
MS	Member States
MSF	Médecins Sans Frontières
NCDs	non-communicable diseases
OECD	Organisation for Economic Co-operation and Development
PHC	primary healthcare
R&D	research and development
SDGs	Sustainable Development Goals
UHC	universal health coverage
UN	United Nations
WHO	World Health Organization



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# European Health Forum Gastein 2015

## Background information

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Across three days in late September - early October, the European Health Forum Gastein 2015 hosted animated discussions between over 500 health professionals. The Forum's review of the underlying issues - demographic, social, scientific, economic, ethical, environmental - was based squarely on the four pillars that support health policy: the EHFG drew on the worlds of research and practice, on the community of patients and civil society, on governmental organisations, and on the healthcare industries - and all of them were encouraged to challenge the status quo.

The discussions extended across some of the immediate pressures in the wider world, including the burning refugees crisis and migration situation in Europe and Middle East. The EHFG 2015 provided expert front-line insights into the access to high-quality healthcare and innovative treatment, and focused on collaboration as a force for advancing the common interest. And input from the next generation was assured by the engagement of the Young Gasteiners, enthusiasts drawn from professions and studies linked to health, who contributed widely to the conference.





# MAIN REASONS TO ATTEND THE GASTEIN FORUM

## NETWORKING

Networking opportunities have been selected as the most rewarding activity



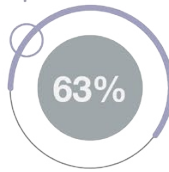
## INFLUENCE

Influence on the European health policy is a reason to attend the EHFG conference



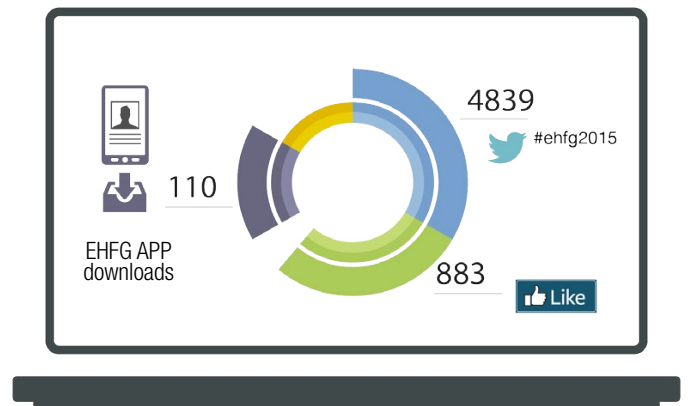
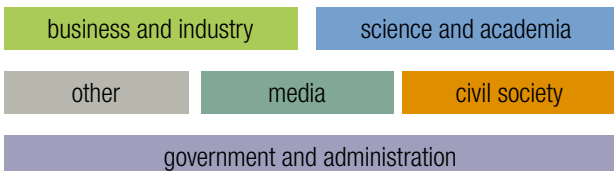
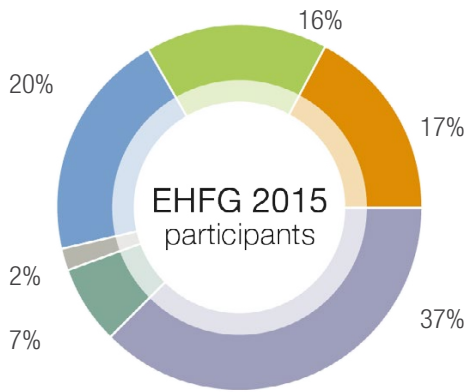
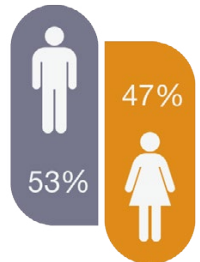
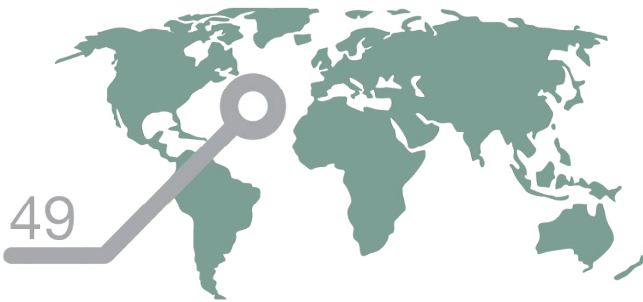
## TOPIC CHOICES

Two third attended because of the programme - timeliness and choice of topics



## LEARNING & SPEAKERS

Over two third attended because of the learning potential and calibre of speakers



# The Gastein Health Outcomes 2015

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## KEY MESSAGES

- This is not a refugee crisis, this is a reception crisis. Human mobility is the new norm in our increasingly globalised world.
- We need “more Europe” - deeper cooperation - to develop a comprehensive, sustainable and collective strategy to respond to the challenges and opportunities presented by key societal challenges. The costs and consequences of non-Europe should be considered.
- There should be clearer, stronger leadership from the EU in those areas where it has a mandate.  
In today’s interconnected world, the EU needs to think globally and act locally.
- We need joint cooperation between all stakeholders on access to medicines and innovation in order to achieve transparency, solidarity and trust in this area.
- A paradigm change is needed in the way we finance, organise and operate our health systems. Particularly to take into account demographic changes, rising healthcare costs, new patterns of disease and a shortage of skilled health workers. Strengthened primary healthcare, a better workforce skills-mix and technological innovations amongst other things can play a major role here.
- We need to build in mechanisms to ensure joint accountability for Health in All Policies (HiAP) across government ministries and European institutions. Improved inter-sectoral collaboration is a pre-condition for health security.
- We must make better use of existing EU mechanisms to address health challenges. We need better implementation of existing regulations and awareness raising campaigns so that citizens and policy-makers are aware of what is already available.
- “Citoyen” participation is required to secure health in Europe: empowered, health literate citizens should be directing decision-making on health.
- We should analyse and act on the data we have, and persist in better translating research evidence into policy recommendations. Where appropriate we should capitalise on new forms of data for health purposes. We need to move towards disseminating health intelligence rather than health information.
- The time for action is now, and in our actions let’s remember the core values and objectives upon which the European Union was founded.



## SINCERE COOPERATION BETWEEN MEMBER STATES

The humanitarian crisis in the Mediterranean continues to present European countries with multiple challenges. The Opening Plenary was devoted to the topic of migration, where it was discovered that 44% of attendees classed themselves as migrants or had a migrant background. There was acknowledgement that echoing the citizen-led *Willkommenskultur* voters were ahead of politicians in responding to the crisis. The initial response was highlighted as key: “This is not a refugee crisis, this is a reception crisis”. And there is no question that this crisis is the new reality: human mobility is a core feature of our globalised world, and the profound geo-political changes the world is currently undergoing will likely only exacerbate the phenomenon.

It is therefore crucial for the EU to swiftly develop a comprehensive, sustainable and most importantly collective response to the crisis: we need More not Less Europe, more cooperation, more understanding, more trust and more solidarity. Besides, the cost of excluding migrants from society is high: we have data to prove that allowing irregular migrants’ access to a basic package of healthcare services pays off in the long-term, and we know that migrants regenerate society and strengthen the workforce - in the healthcare sector alone we are looking at a shortage of one million workers by 2020.

Most importantly we need more leadership in Europe to recognise common European problems that require common European solutions. The Lisbon Treaty does not stop us from doing more if we so desire. Examples include the Cross-border Care Directive that offers possibilities for deepened cooperation between Member States; on Health Technology Assessment where long term structural reforms are needed, and voluntary cooperation on pricing with the example of countries using their joint purchasing power to negotiate better deals on vaccines and pharmaceuticals. “More Europe” is also called for in the area of personalised medicine so that we can manage together the complex challenges such as affordability, fair pricing and regulatory issues offered by technological innovations in this area.

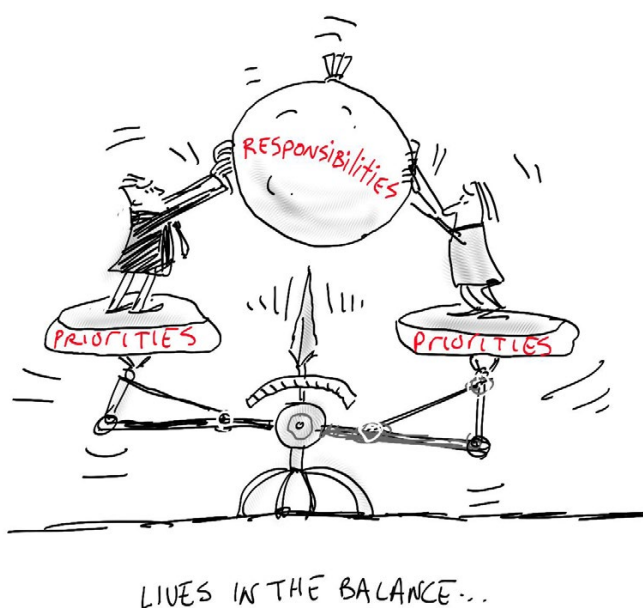
Access, affordability and equity were some of the keywords of the conference, and particularly so in discussions around access to medicines. There were calls for increased partnership working between industry, Member States and payers to address the issue. Debates on pricing included calls for transparency so that Member

States could obtain a common understanding of prices, versus the autonomy of Member States and the potential benefits of secrecy in this area. Disparities across Europe were also discussed in the context of clinical outcomes and mortality and access to innovation, with many of the CEE countries at the worst end of the spectrum. A pan-European strategy was called for to tackle the issue of increasingly expensive innovations. Health systems can further deliver improved outcomes by addressing inefficiencies, waste and reducing medical error; thereby freeing up money that can be put where it is needed.

The costs and consequences of “Non-Europe” in public health, both in responding to crises such as the “reception crisis” as well as in taking action on ongoing public health issues such as tackling risk factors in Member States that contribute to chronic diseases and multi-morbidities should be borne in mind.

## GOOD GOVERNANCE MODELS FOR (A SOCIAL) EUROPE AND BEYOND

There were strong renewed calls for clear leadership where the EU has a competence to ensure a balance again between political vision and technocracy. We also need a major shift in the way we finance, organise and operate our health systems. One specific example was how health systems need to adapt to the challenge of treating patients with multi-morbidities, with a move away from a disease-focused to a person-centred approach. Strengthened primary healthcare has a role to play here, it was



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asserted, with a systemic approach needed and better training and incentives for General Practitioners plus a more diverse workforce skill-mix comprising more integrated, multi-disciplinary teams. And evidence in the form of good quality data will help support decision-making: we need health systems performance assessment to know what we get for the money invested.

In general there was a consensus that between the different Member States - especially old and new - there should be an upward social and health convergence.

Innovations in eHealth and mHealth were also highlighted, with calls for governments to provide information systems and infrastructure and the right incentives necessary for health professionals and managers to encourage take-up.

In the context of global health, it was agreed that the global health crisis remains a governance crisis. The challenge faced by Europe of developing a public health approach that responds to a globalised world was considered, in light of the observation that with an increased number of people on the move the global is now here and not there.

Opportunities available to the EU were reflected upon. In terms of global health, Europe could and should exercise a leadership role, in areas such as the Sustainable Development Goals, which have both a domestic EU dimension in addition to their overseas impact and give the EU the opportunity to lead on new development models. Financial leadership opportunities are already present considering the EU is the biggest aid donor in the world. The challenge of health security represents another leadership opportunity where the EU must think globally and inter-connectedly but act locally: the Ebola crisis highlighted that weak, underperforming health systems “somewhere” have the potential to affect everywhere else.

## APPLYING THE CROSS-CUTTING NATURE OF HIAP

“Health in all policies or health in all politics?” Participants of the Thursday Plenary session which was focused on the topic of Health in All Policies (HiAP) agreed there was a need to move on from a technocratic to a political vision of HiAP: after all, health is a political choice. Smart, inclusive and sustainable growth strategies always include health, and in order to be re-elected politicians

need to increase well-being in every sense. Investing in health systems translates into investments in people’s lives. So HiAP is a EU Treaty obligation, makes economic sense and should be self-evident. Then why is it inconsistent, loosely applied and not adhered to? Why is it that we are better at HiAP in crisis situations than in routine practice?

The words “responsibility” and “accountability” arose frequently in discussions. Which government ministers (beyond the health minister) feel responsible for health outcomes? Some ideas put forward were more checks and balances across policies, such as consultations and Health Impact Assessments, and tackling policy incoherency, including a recognition that where public health conflicts with industrial interests self-regulation rarely works. The health sector should be more transparent about its work and make better use of evidence and big data to prove its effects. A concrete example of improved inter-sectoral collaboration discussed in a couple of sessions was the nexus between social services and health services. Health literate politicians and populations are needed to truly have a democratic approach and take HiAP seriously.

Without inter-sectoral collaboration, especially collaboration in healthcare delivery for patients through innovative partnerships, health security cannot be achieved.

## MAKING FULL USE OF EXISTING EU-REGULATIONS

In delivering “more Europe” we need not reinvent the wheel but should revisit, fully implement and make best use of existing EU-regulations. EU funds need to be more accessible, flexible and timely. Sometimes crises are of our own making, the result of or worsened by our inability to quickly deploy financial instruments at short notice. Flexible mechanisms that can be rapidly deployed are necessary in a world of frequently changing “theatres of crisis”.

Health security is never-ending work and mechanisms need to be updated and sustainable to be effective. Member States need to make use of the European Semester process and its Country Specific Recommendations for Health to optimise health system performance and leverage results for health. Many sessions touched on the Cross-border Care Directive, which is currently under-exploited by Member States. Optimal implementation of the

Directive is needed, and there is the potential of eHealth solutions as a tool to fight the challenge of bureaucracy in cross-border care.

Better implementation was also called for in the context of the International Health Regulations (IHR), with agreement that “The only certainty about the next outbreak is that it’s coming!” and that it would be a mistake to let the momentum built as a result of the Ebola outbreak pass without taking proactive steps for increased preparedness.

## EUROPE IS ABOUT THE EUROPEANS

“Participation” was added as a fourth “P” to the triumvirate of “Prevention, Promotion and Protection”. Without Participation there is no way to secure health in Europe. The importance of European citizens being at the heart of (political) decision-making processes was echoed in many of the conference sessions. In access to new and innovative medicines, technologies and healthcare it was argued that empowered citizens should be at the forefront of considerations to develop user-friendly, person-centred innovations and be included in a dialogue on costs as well as value. In order to participate effectively citizens need more health information and

higher levels of health literacy. To achieve greater health literacy a holistic, bottom-up approach should be adopted: this will help create the “European Citizen” - the educated citizen who can make political decisions.

There is an implementation and utilisation gap in health information, and it was considered worth analysing and acting on existing data before collecting more. A goal in this area should not be health information but health intelligence, encompassing the appropriate dissemination and utilisation of available data based on the target audience.

Data also needs to be fit for purpose, it was argued: demographic changes mean many patients have multi-morbidities but most clinical research is still based on single diseases. There were some calls for an EU-led Joint Action on health data, and better translation of health data into policy processes.

The fact that we should remember the values and objectives upon which the European Union was founded was frequently mentioned at the EHFG 2015. The current situation in Europe is testing the Union itself as well as its values and objectives, particularly that of solidarity, to the core.

# Young Forum Gastein Network 2015

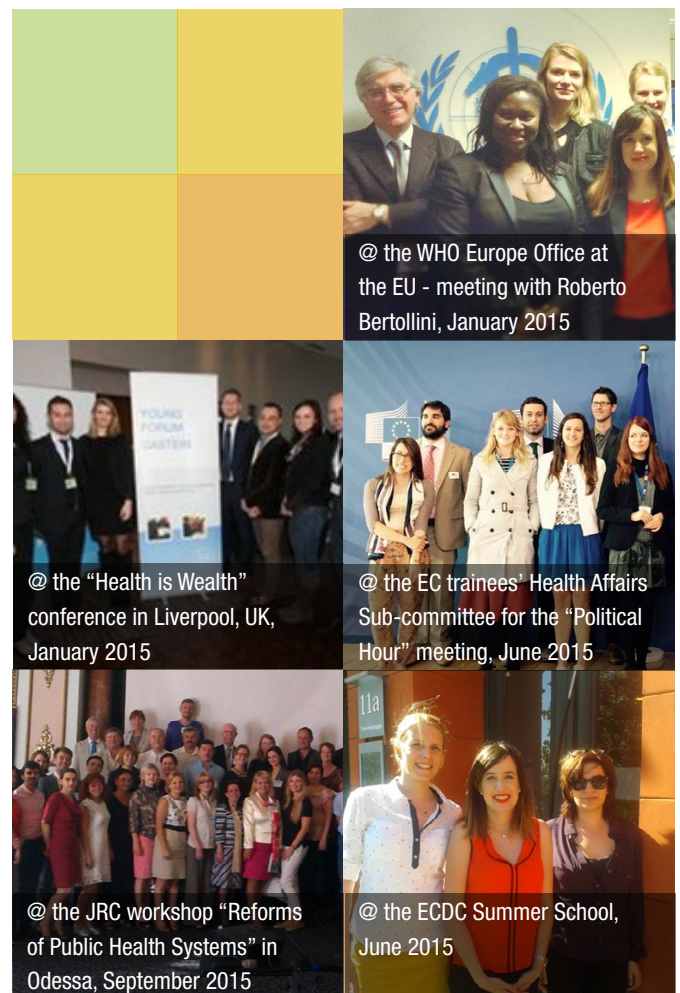
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The Young Forum Gastein initiative is a joint project of the International Forum Gastein and the European Commission.

The project brings together promising young health professionals from different backgrounds and with diverse professional experience to participate in learning and networking activities in the sphere of health.

In the framework of an engaging and stimulating dedicated programme, the scholarship offers a unique opportunity to learn from and network with colleagues from across Europe, develop important public health competencies such as the ability to build alliances and partnerships, learn advocacy and persuasion skills and develop presentation and communication skills and last but not least to have privileged exchanges with senior policy-makers and academics in special closed workshop sessions.

In 2015, 76 young professionals working in the field of health from Member States of the European Union and beyond were invited to attend the 18th EHFG conference. But the YFG network was also very active throughout the year and in the photographs on these following pages you can see a glimpse of the activities they were involved in 2015.







@ the YFG Poster Exhibition presentation, EHFG 2015



@ the YFG skills-building workshop - moderation and facilitation techniques, EHFG 2015

@ one of 30 ONE-TO-ONE mentoring sessions with senior delegates, EHFG 2015



@ an informal meeting with EU Commissioner Vytenis Andriukaitis, EHFG 2015



@ the career talk with EC officials - senior vs. junior perspective, EHFG 2015

@ the WHO Europe workshop: Roadmap to enhance evidence-informed policy-making, EHFG 2015



@ the Taiwan Global Health Forum, Taiwan, November 2015

@ the panel during the "Health Equity in an Unequal World" event, Stockholm, November 2015

Young Gasteiners have a busy schedule during the EHFG conference. It includes participating in the general conference programme, as well as attending specific Young Forum Gastein meetings and working groups and completing tasks.

Within the Young Forum Gastein programme various activities took place. Scholars had the opportunity to attend a career talk with a DG SANTE representative and join one-to-one mentoring sessions with almost 30 senior delegates representing the four EHFG pillars. An additional two skills-building workshops rounded off the programme: one on facilitation and moderation and another with a member of the European Personnel Selection Office (EPSO) on the EU Competitions, to enable scholars to understand the EU personnel selection process.

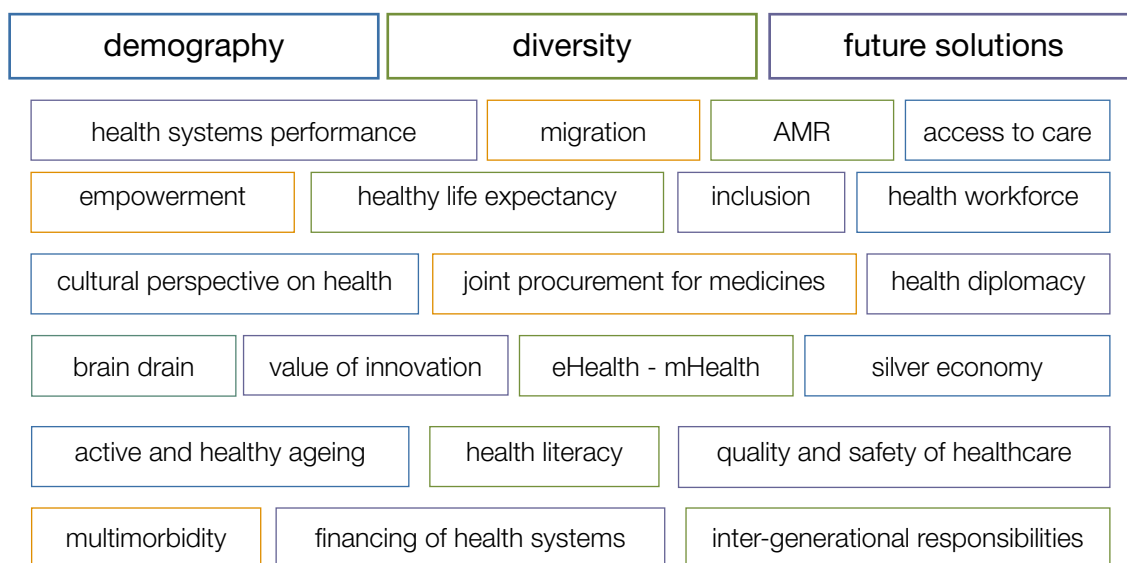
Members of the Young Forum Gastein Network are playing an increasingly important role both in the organisation of the conference and in increasing the overall visibility of the YFG initiative. At the EHFG 2015 conference Young Gasteiners participated as speakers or panellists in a number of parallel forum sessions and workshops. Two Young Gasteiners evaluated the applications for the 2015 European Health Award and moderated the Award Ceremony.

Following the development of a Young Forum Gastein strategy in early 2015, the Network continues to go from strength to strength, with the young health professionals participating in a range of summer schools, conferences and workshops throughout the year. Thanks to all members who contribute so enthusiastically during the conference and throughout the year!

Our special thanks go to the following supporters of the initiative in 2015:

- European Commission
- ECDC
- ASPHER
- Health Promotion Administration, Taiwan, R.O.C.

We look forward to further building the initiative throughout 2016 and beyond!



The keywords above point to some of the thematic areas we feel will fit in well with our conference main theme. They are meant as “food for thought” and are not to be understood as a comprehensive list of topics acceptable for the conference – we are open for suggestions!

28-30 SEPTEMBER 2016 BAD HOFGASTEIN, AUSTRIA  
19TH EUROPEAN HEALTH FORUM GASTEIN

## #ehfg2016

# Demographics and Diversity in Europe - New Solutions for Health

Europe is undergoing a period of profound demographic change. Life expectancy is reaching new highs, precipitating the challenge of ageing societies, changes in family and household structures, and corresponding questions around intergenerational responsibilities. Getting older is in itself a positive development. But as the most important risk factor for many diseases is age, will we see more multimorbidity and increasing demands for care, and if so how will we finance these? And how will we manage health services for more people with greater needs? Fertility patterns are also changing, with most countries in Europe experiencing fertility below the replacement level. The ongoing phenomenon of increased migration will remain top of government agendas in 2016. How can we best manage the increasing diversity in populations, cultural differences between them and mitigate the negative effects of the „brain drain“ on the health systems of those countries experiencing high migration? Furthermore what measures can we take to secure equitable access to innovative health care for all Member States? Conversely, there is much discussion about the challenges of demographic change, but what might be the advantages which could lead to important opportunities for us to seize?

Demographic change underlies many of the issues we are facing in Europe today and which we will contend with in the coming years, with these phenomena all exerting different pressures on European health systems. But demography is not destiny and by pro-actively considering the challenges and highlighting the often neglected opportunities presented by demographic change and increased diversity in societies we can better influence its outcome. Innovations and visionary foresights are needed to turn these challenges into opportunities for sustainable solutions. We invite you to join us to consider these issues at the EHFG 2016.





# PLENARY SESSIONS

OPENING PLENARY  
Securing Solidarity in Europe.  
From Mare Nostrum to Mare  
Europaeum

THURSDAY PLENARY  
Achieving Health in All Policies

CLOSING PLENARY  
Securing Health in Europe.  
Balancing priorities, sharing  
responsibilities

part I

# Securing solidarity in Europe

From Mare Nostrum to Mare Europaeum

Helmut Brand, President of the International Forum Gastein, welcomed the delegates to the 18th European Health Forum reminding them of the relevance of this year's topic "Securing Health in Europe. Balancing priorities, sharing responsibilities", and how it had been given new meaning recently in the light of the refugee crisis. Even if regionalism is back on the agenda, as many elections indicated, Brand urged that we need more Europe now than ever, especially for securing health. As the demographic and economic situation is changing, and there are new health and social challenges, we need to find European solutions to this global crisis.

Josep Figueras, Director of the European Observatory on Health Systems and Policies and moderator of the session, pointed out that the refugee crisis is a test of the European value of solidarity. Figueras introduced the opening plenary session as an opportunity to discuss the refugee crisis from the health perspective: the session was organised with three presentations to set the scene and better understand the situation of refugees in Europe, followed by a panel discussion. The audience had the opportunity to participate in the session through an interactive web-based system, and through answering questions. The answer to the first set of questions (44% of those at the plenary have lived abroad at some point of their lives) made it immediately clear that migration is a relevant factor for many of our participants and for our society at large.

A short presentation on the refugee crisis followed that indicated some of the numbers: 500,000 people have arrived so far to the EU in 2015, 3,000 went missing during the journey. The final powerful message was that "No human being is illegal".

## THE SCENARIO

In a video message Volker Turk, Assistant High Commissioner for Protection, Office of the United Nations High Commissioner for Refugees (UNHCR), declared that human mobility has become a defining feature of our world, but the positive contribution that refugees can offer to host societies is often overlooked. He reminded us that it is also important not to misunderstand the numbers: Europe is currently receiving only 1% of all the Syrian refugees.



According to Turk, the world is undergoing profound transformations at all levels (geopolitical, economic and technological) and this situation calls for international solidarity and cooperation. As a final recommendation, Turk pleaded that “we need to build upon our European tradition to deal with this crisis and rebuild control of the situation, and avoid further loss of life”.

Martin McKee, Professor of European Public Health at the London School of Hygiene and Tropical Medicine, highlighted a key concept that was afterwards mentioned several times in the panel discussion: “Each one of these refugees has a name. There are names behind numbers”. After presenting some numbers about the scale of the crisis, McKee stressed the fact that we know that most refugees are of working age and, contrary to what is feared, they do not bring infectious diseases with them: their greatest problem is mental health, stemming from living in war zones and undertaking hazardous journeys to seek safety. In a final statement, McKee explained that despite politicians’ mundane struggle to deal with the crisis, there are many people in European countries that offered to host refugees in their homes. This tells us a lot about European values and citizens’ desire to take action to help those in need while their governments pontificated about the best course of action.

The last presentation to set the scene was provided by Meinie Nicolai, President of Médecins Sans Frontières (MSF), Operational Centre Brussels, who highlighted the humanitarian consequences of EU policies on the refugees’ health and well-being. After presenting the whole range of activities that MSF put in place to deal with people in conflict zones and in refugees camps, she strongly expressed her main argument: “What happens nowadays in Europe is not a refugee crisis but a reception crisis”. According to Nicolai, the EU is failing in its response and at the same time it is creating new vulnerability. The migrants often left their homes being healthy, but the journey and the bad reception conditions at their arrival points in Europe make them ill. People lose their human dignity on the way because of violence, ill-treatment, abuse and sometimes even torture. In conclusion, Nicolai reiterated that the reception of migrants in Europe is a policy-made crisis and that current reception conditions are unacceptable: EU policies are creating needs instead of solving them, for example by excluding refugees from access to primary healthcare because of a lack of documents.



Drawing on Nicolai’s core message, Figueras opened the panel discussion in the light of an interesting result from a question to the audience: 96.4 % of attendees agreed that the health sector should be involved in policy decisions on refugees. Thus, what is the role for the health sector in this crisis?

## PANEL DISCUSSION

Sabine Oberhauser, Federal Minister of Health of Austria, reminded the audience that Austria is currently receiving a large number of refugees and doing its best to meet their needs. Most Austrians understand the situation, but there are also people who do not want their money to be spent on migrants. In order to change this attitude, Oberhauser stressed the need to show that there are people behind the numbers and that refugees are not a danger for us. Answering to the question on how to make this case with other ministerial colleagues, Oberhauser replied that the debate is not easy, as different ministers have different problems, particularly the Interior Minister who is dealing with police and security issues and finding places to accommodate refugees. The Minister concluded that although the financial situation is challenging, refugees are people who need to be helped.

According to Christopher Fearn MP, Parliamentary Secretary for Health, Malta, the health sector has failed to take leadership in managing the refugee crisis. In his view this is primarily a

medical emergency and not an economic or security issue. The priority is to save lives. That is why, according to Fearné, the whole debate on refugees should be run by the health sector. A key problem for Fearné are cultural aspects, for example potential misunderstandings between the health professionals from the recipient country and the migrants. Fearné concluded by underlining the importance of international collaboration and agreement to deal with this crisis: "Solidarity needs to crystallise into something concrete and at the moment this is not happening very much".

Martin Seychell, Deputy Director-General, DG Health and Food Safety (DG SANTE), European Commission, mentioned that the current crisis is routed in the EU structures, which are not quick enough to respond to emergencies: "The EU needs to promote a holistic view to deal with this crisis from a multidimensional perspective and collaborate with international organisations. All our policies need to be grounded in values and not just bureaucracy". "Fast" is the key word for Seychell: "By understanding the needs quickly, we can help refugees and we can help health systems. We need fast mechanisms to deal with the crisis quickly". In conclusion, Seychell affirmed that the health sector needs evidence to present to the rest of the system and to support decision-making. As the current crisis is multidimensional, no sector can deal with it on its own. A final positive view: "The big advantage of Europe is that there are structures in place for countries to collaborate".

Sharing his experience on the refugee crisis, Santino Severoni, Coordinator Public Health and Migration, WHO Regional Office for Europe, explained that access to health services is one of the key problems: depending on their status people have different access to services. According to the UNHCR Refugee Convention of 1951, refugees are entitled to health and social services on an equal basis, but in fact the provision of services varies from country to country. For refugees it is also very difficult to navigate their reception country's health system, as it is not shaped to offer assistance to a diversified population. Severoni stated that many people who arrive in the EU do not apply for asylum or are not accepted, or else for whom the process to acquire refugee status takes a lot of time. This is specifically an issue in two thirds of EU countries which offer only emergency health services for those without refugee status. Besides the humanitarian aspects, this is also not a cost effective way to deal with refugees because "provision of primary care services would cost less and would avoid more expensive treatments in the future". In a final remark Severoni stated that "when it comes to refugees, health systems work in a state of emergency, with little forecasting and strategic planning. It is a time to change that".

Figueras then gave the floor to Constantinos Manolopoulos, Interim Director, European Union Agency for Fundamental Rights (FRA). According to Manolopoulos, it is very important for European countries to deal with migration not just as an emergency issue.



Refugees, migrants and asylum seekers are not interchangeable terms. The following is a brief explanation of the very different legal definitions:

A **refugee** is a person who has fled his or her country and cannot return because of a well-founded fear of persecution due to their race, religion, nationality, or membership of a particular social group. Refugee status is assessed by the UNHCR or a sympathetic state.

An **asylum seeker** is someone who says he or she is a refugee and is seeking asylum in another country, but whose claim has not yet been definitively evaluated.

A **migrant** is someone who chooses to move in order to improve the future prospects of themselves and their families.

Source: Médecins Sans Frontières  
URL: <http://www.msf.org/topics/mediterranean-migration> (15.03.2016)

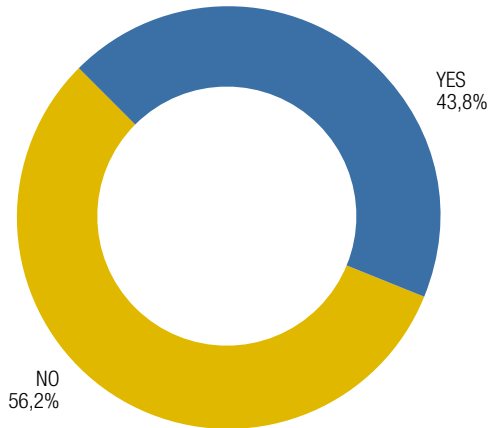
# VOTING RESULTS

Participants of the Opening Plenary session were asked to answer several questions relating to the subject of the debate.

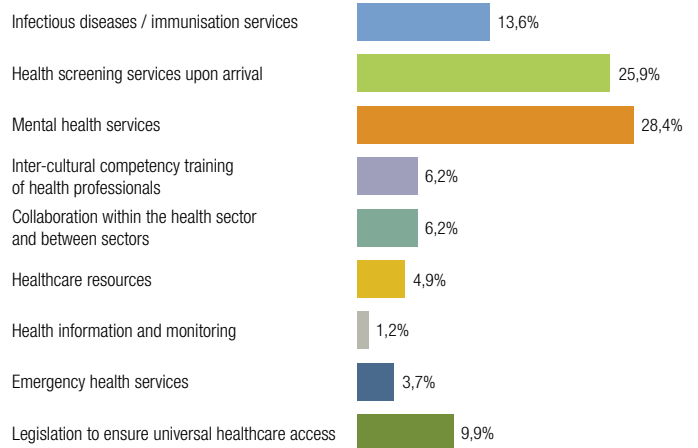
To access full voting results please visit our EHFG 2015 archive.



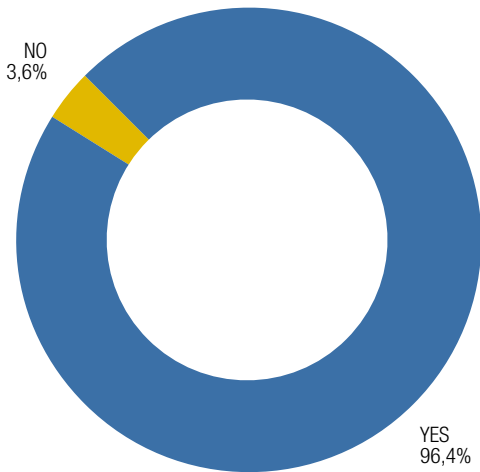
Are you or have you been a migrant (lived one year or more in a country other than the one you were born in) and/or are your parents migrants?



What are the three main priorities for strengthening the health systems' capacity to respond to the refugee crisis?

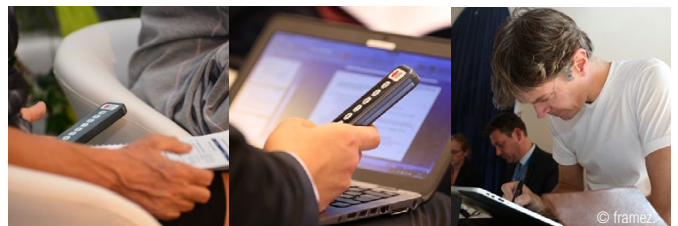
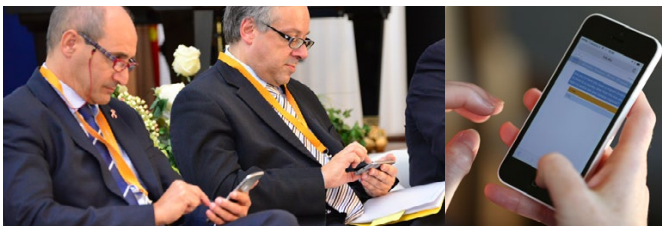
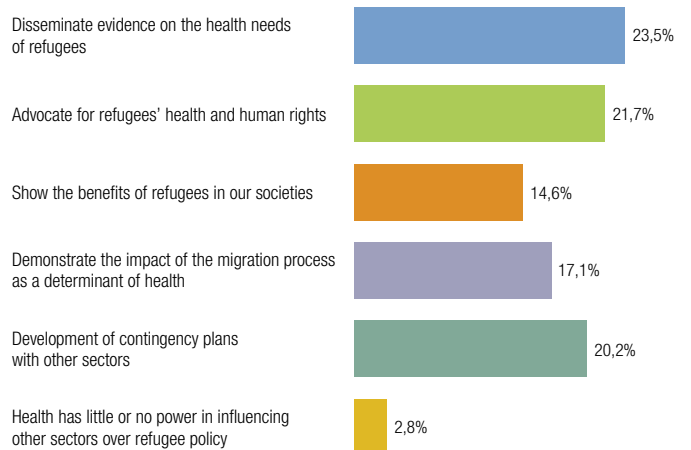


Do you agree with this statement: "The health sector should be involved in policy decisions on refugees".



How can the health sector engage with other sectors to ensure the needs of refugees being met?

Choose the three most important ones:





The Agency prepared a study on the costs of exclusion of migrants from healthcare. The results show that the costs of healthcare over a lifetime can in fact be decreased if migrants are provided with basic healthcare and prenatal healthcare. The key issue for Manolopoulos is integration: "Migration is also an opportunity for us to renew our society because the majority of migrants are younger than us. We need to integrate them properly into our societies".

Figueras wrapped up the discussion and asked the panellists for a last round of comments in the light of some questions provided by the audience that could be summarised as a "call for action". Minister Oberhauser affirmed that in order to put solidarity into practice and to better deal with migrants, Austria is working with NGOs that have specific practical experience in dealing with similar issues. Fearn explained how Malta learned from a mistake of nine years ago when it was decided to give migrants the same level of healthcare as the local population without taking into account the big cultural differences that need to be addressed. "It is not enough offering a service, we need to make it accessible", he concluded. Seychell reiterated the concept that migration is a key feature of the 21st century and requires a proper policy response. He pointed out that the Commission has proposed an agenda on migration, which aims to manage this issue, instead of only reacting to it on an emergency basis. Severoni commented that too many public health activities in dealing with migration aren't evidence-based and there are also problems in communicating evidence where it is available. Communication and contingency planning are key actions to be taken. Manolopoulos added that the right to health is a human



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right. This should be understood widely, as migration will be on Europe's agenda for years to come. McKee stressed the fact that this crisis affects the whole of Europe although some countries are more directly involved, while Nicolai reiterated her main argument: "Policies of reception are creating the crisis and now that the cold is coming we need to act fast to avoid further deaths".

At the end of the session, President Brand thanked all speakers for their insightful contributions and the audience for their active participation in the discussions. He summarised the key points raised in the discussion as follows:

- When dealing with the crisis, key EU values should be remembered;
- Voters have been ahead of politicians, welcoming migrants and offering help;
- This is a reception crisis, not a refugee crisis, and the EU was not prepared for it;
- Solidarity between Eastern and Western Europeans should be ensured and Europe's response should be a coordinated one;
- We need an EU network of interpreters, inter-cultural mediators and psychologists to help overcome cultural barriers, and a EU fast mechanism to fund these initiatives;
- Migration is a global issue but the EU should lead by example in terms of how to manage it;
- Access to health care services should not be dependent on a migrant's status;
- Access to health care pays off also economically in the long term;
- Communicating with other policy areas is difficult but manageable.



"VOTERS ARE AHEAD OF POLITICIANS"

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16 SEPTEMBER 2015



# MIGRATION

## FACTS AND FIGURES

AS OF 16 SEPTEMBER

A TOTAL OF

# 411,600

REFUGEES AND MIGRANTS

HAD ARRIVED IN EUROPE BY SEA

121,500 IN ITALY  
288,000 IN GREECE  
123,000 IN SERBIA  
414,000 IN GERMANY

UNHCR

### MIGRATORY ROADS IDENTIFIED FOR AN ENHANCED RCRC MOVEMENT RESPONSE TO MIGRANTS VULNERABILITIES AND NEEDS

UNITED KINGDOM  
ITALY  
FRANCE  
SPAIN  
HUNGARY  
SERBIA  
MACEDONIA  
GREECE  
TURKEY  
LEBANON  
JORDAN  
LIBYA  
EGYPT  
MOROCCO  
TUNISIA  
MAURITANIA  
MALI  
NIGER  
CHAD  
SUDAN  
ETHIOPIA  
SOMALIA  
SENEGAL  
GAMBIA

● IFRC Africa zone  
● IFRC MENA zone  
● IFRC Europe zone  
→ Migratory flow  
⊗ Sensitive cross point

# +5,000

PEOPLE

ARE BELIEVED TO HAVE LOST THEIR LIVES WHILE ATTEMPTING TO REACH EUROPE VIA THE MEDITERRANEAN SEA IN THE LAST 18 MONTHS

# 2,800

OVER

# PEOPLE

WHO ATTEMPTED THE CROSSING OF THE MEDITERRANEAN OR WERE RECORDED AS MISSING SO FAR IN 2015

# 1,779

PEOPLE DROWNED DURING THE SAME PERIOD IN 2014

ICM

# 121,500

HAVE ARRIVED IN ITALY IN 2015

# 11,020

WERE ASSISTED BY THE ITALIAN RED CROSS AT THEIR ARRIVAL

IN JUNE 2015

ITALIAN RED CROSS

# 411,600

PEOPLE HAVE CROSSED THE MEDITERRANEAN SO FAR IN 2015

# 193,600

PEOPLE MORE THAN THE TOTAL FOR THE WHOLE OF 2014 (218,000)

ICM

IN 2015

# 206,510

SYRIANS

CAME TO EUROPE'S SHORES – THE SINGLE LARGEST GROUP BY A CONSIDERABLE NUMBER, ACCOUNTING FOR 51% OF ALL ARRIVALS

### TOP 5 NATIONALITIES ARRIVING BY SEA

SYRIA	51%
AFGHANISTAN	14%
ERITREA	8%
NIGERIA	4%
PAKISTAN	3%
(OTHERS)	

UNHCR

# Achieving Health in All Policies

In her opening speech, Ilona Kickbusch, Director of the Global Health Programme at the Graduate Institute of International and Development Studies in Switzerland, pointed to the fact that the concept of Health in All Policies (HiAP) has been on the health policy agenda for many years through a series of publications, such as the Ottawa Charter for Health Promotion or the Review of Social Determinants and the Health Divide in the WHO European Region. This long-standing discussion about the health of European citizens and the necessity of a healthy workforce provided grounds for World Health Organization's current health policy framework Health 2020.

As Kickbusch stated, HiAP via intrasectoral and cross-governmental action is now as important as ever because "the crisis is the new norm". Governments in Europe have been challenged by the 2007 financial crisis and now need to show resilience in dealing with the current refugee crisis. New questions arise:

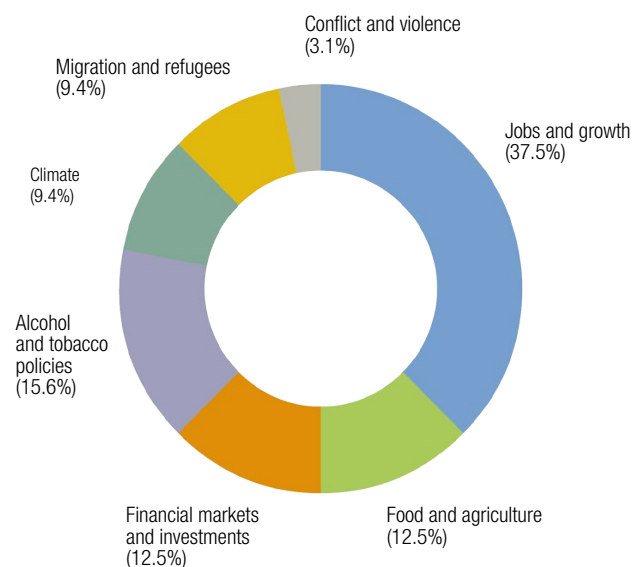
*Does universal health coverage make economic sense?*

*How do we best make that investment and where?*

*How can the WHO and the EU assist national governments in implementing health in all policies?*

To kick off the discussion, the audience were asked to participate in an interactive vote "If you could choose only one policy area, where would you set the priority for the EU to engage in Health in All Policies?" The participants' priorities would be as follows:

If you could choose only one policy area, where would you set the priority for the EU to engage in Health in All Policies?



The aim of HiAP is to enhance health promotion and prevent illness as well as to ensure a high level of health security and the delivery of high quality universal care. Guided by the discussion between senior representatives of the European Commission, the WHO Europe and the healthcare industry, this plenary explored how to achieve HiAP and coherent European inter-sectoral action.



Ilona Kickbusch, Piroška Östlin and Andrzej Rys

## HOW CAN WE APPROACH INTER-SECTORAL ACTION AND GOVERNANCE FOR HEALTH?

The Austrian Federal Minister of Finance Hans Jörg Schelling gave the keynote address via video. He reminded us of the important goal of searching for cost-effectiveness while ensuring a healthy society. National states have the objective not to spend more than they can afford, and therefore cost-effective measures are necessary at a reasonable price for society. Schelling gave the example of the smoking bans, which were introduced in restaurants at the end of heated debate in Austria. He further noted that from 2004-2011, whereas life expectancy increased by two years, the quality of life did not which highlights what health systems in Europe still need to improve upon.

Piroška Östlin, Acting Director for Policy and Governance for Health and Well-being at WHO's Regional Office for Europe, made it clear that WHO Europe is strongly investing in supporting Member States to reach the goals set by Health 2020 as well as HiAP. She discussed why health is a political choice - many of the determinants of health are influenced by factors outside of the direct scope of the health sector; these social determinants of health (SDH) are shaped by political decisions. Because inter-sectoral action is very complex, strong political commitment is needed to create synergies across sectors. Health 2020 calls for the health sector to reach out and work with key players from other areas such as academia, the media, and industry. She reminded us that this issue was also stressed at the recent regional meeting in Vilnius. According to Östlin, health is critical to impact change and should even be promoted as the outcome of government action.

Andrzej Rys, Health Systems and Products Director at the Directorate General for Health and Food Safety (DG SANTE), discussed the meaning of a European Union for health and how the new European Semester has helped push the HiAP agenda. He highlighted the very strong wording of Article 168 of the Lisbon Treaty, and that EC President Jean-Claude Juncker has made collegiality and collaboration between Commissioners a priority. At DG SANTE in particular, a number of cross-sectoral actions have been put in place such as the digital single market strategy, as well as investments in telemedicine, and e-platforms. Finally, Rys referred to the Ebola crisis response, as an example of the effectiveness of cross-sectoral approaches in addressing health threats and security.

## BUT DO WE HAVE THE RIGHT TOOLS TO ASSESS HEALTH IN ALL SECTORS?

Nina Renshaw, Secretary General of the European Public Health Alliance (EPHA), commented on the important role played by civil society and NGOs in drawing attention to some of the current roadblocks to implementing HiAP.

In practice, governmental inconsistencies in certain sectors can impact on Member States' capacity to implement national public health initiatives. For example, the EU bans the institution of tax variations for liquor products based on the degree of alcohol. Inconsistencies in governmental action do not necessarily stem from a lack of scientific evidence, but arise when public health interests and industrial interests collide, especially within the frameworks of the Common Agricultural Policy, EU internal market regulation, or the TTIP mandate. Renshaw further noted that in the mid 1990s there were annual checks on how well the EC was implementing HiAP, which to her regret have been discontinued. This is a question of accountability. She concluded by asking "Do finance ministers also feel responsible for the increase in healthy life years?"

Only when we all agree that health is a worthwhile investment and that we are all accountable for it, will we be able to enact change and progress."



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## HOW CAN WE VIEW HEALTH AS A BETTER INVESTMENT?

Richard Bergström, Director General of the European Federation of Pharmaceutical Industries and Associations (EFPIA), explained that the health innovation sector, especially with regard to digital health information, is one of the most rapidly growing sectors. Europe needs to play a role in spearheading and supporting innovation in the sensor technology, the use of big data or new IT solutions for patient-reported outcomes. Bergström also urged all policymakers to view pharmaceuticals as more than just an expense. He added that “we should recognise that technology and entrepreneurs can produce innovation and investments in health. This will not only better general health outcomes but also bring new jobs and ultimately growth to Europe.”

Terje Peetso, Policy Officer at the Health and Well-being Unit of DG CONNECT, European Commission, discussed some of the ongoing projects to support digital health, e-identification of patient records and telemedicine in tandem with players outside the health sector such as the Space Institute. She asked: “How can we use space technology to improve health? What can we learn from other sectors?” Peetso noted that technological innovations in other areas are a worthwhile investment for the healthcare sector because these can play a key role in improving healthcare delivery and access to care. For the implementation of the cross-border healthcare directive, for example, broader use of digital technology is crucial. This, for her, is HiAP in practice.



Nina Renshaw,  
Terje Peetso

Twitter team:  
Maggie Davies and  
Shioban O'Connor

Live Cartoonist:  
Floris Oudshoorn

Christoph Schwierz, from DG Economic and Financial Affairs (DG ECFIN), European Commission, explained that from a financial perspective the necessary structures are in place to support HiAP. The European Semester is taking health and health systems into account and country-specific recommendations help Member States in turn to address their inefficiencies in order to make HiAP a reality. Regarding HiAP, Schwierz stated the need to “put the promised land of health in all policies to good use and into reality.”

## WHO IS TO BE HELD ACCOUNTABLE?

Panellists agreed that we need to make sure that there is strong political commitment at both the EU and the national level supported by measurement indicators and a consensus on what HiAP means across sectors and what is the European added value. Bringing the discussion back to the Social Determinants of Health, an online commentator noted that, “Health in All Policies should not just focus on sickness but also on creating conditions for people to be healthy (for example jobs, housing)”.

The post-Ebola reflection on global governance and the current refugee crisis should help us to exploit a new sense of purpose to foster HiAP. We need to ensure policy coherence across sectors, accept the limits of our work and focus on areas where we can learn from each other and share resources for better results. Health in all policies is an opportunity for us to reaffirm the essential values of solidarity, democracy, and accountability, which are at the core of the European model.

## CONCLUSION

Greater coherence in European HiAP will be defined by the creation of synergies across public policy areas and collaboration between key players from civil society and the sectors of health, finance, research and development, industry, and employment. The health sector can be an important driver for growth and innovation but as underlined by Kickbusch: “If we want to move the health agenda forward and ensure health in all policies, we need health literate citizens. And if health is a political choice, we also need health literate politicians.”



# Securing health in Europe

Balancing priorities, sharing responsibilities

After three days of stimulating conference sessions, the Closing Plenary served to summarise what had been discussed throughout the conference, in addition to giving pause for thought and to celebrate success stories.

The session was moderated by David Rose, Director, LACS Training, who led the delegates through the two hour round up, which was split into four distinct sections.

## EHFG 2015 VIDEO REFLECTION

First up was Tamsin Rose, Non-resident Fellow, Friends of Europe, who introduced the video reflection segment, a Gastein Forum tradition that saw a revamp this year, to include punchy content and sharper editing. Rose presented two videos, the first of which highlighted the debate on the urgency of the refugee crisis, of which the main message was: “This is not a refugee crisis, this is a reception crisis”.

In short, with greater solidarity and safer passage, refugees would be afforded the right to be treated as the human beings they are, rather than an imposition. Without safe passage and with the poor levels of sanitation currently seen in refugee camps, we are creating more problems than we are solving.

The second video drew attention to the fact that for health to be truly in all policies, greater inter-sectoral and governmental action is required, summarising that the EU should not restrict its action

to European borders, but should aim to strengthen health systems globally. The Ebola outbreak is a prime example, beginning as a crisis in one country, quickly spreading throughout the world, and creating an international threat to health security.

The presented videos were the first two in a series of seven, which can be found on the EHFG website.

Migration And Health ▶ 01	Health In All Policies ▶ 02	Securing Health In Europe ▶ 03	Access To Medicines ▶ 04
Sustainable Healthcare Systems ▶ 05	Technology And Innovation ▶ 06	Public Health Threats ▶ 07	VIEW OUR EHFG 2015 WEBCASTS FOR MORE

## EUROPEAN HEALTH AWARD CEREMONY

Next on the agenda came the prestigious European Health Award Ceremony, established in 2007 and sponsored by the Austrian Federal Ministry of Health and the Forum of the Research-based Pharmaceutical Industry in Austria (FOPI).

The award is based on selection criteria including that the initiative should be innovative, sustainable, and transferable and focused on public health or healthcare delivery and that it should address an important threat to population health.

Two Young Forum Gastein Scholars played an active role in the proceedings, evaluating the candidate projects and having the honour of announcing the winner from a shortlist of six projects.



The jury complimented the winning project for its low cost, high transferability and excellent effectiveness.

The winner and recipient of 10,000 Euro was the “HEALTH WITH MIGRANTS FOR MIGRANTS IN EUROPE PROJECT” (MiMi), which was commended for reaching around 90,000 migrants since its implementation in 2003 in Germany, helping to address migrants’ challenges and improve social integration. Ramazan Salman, CEO and Co-founder of the Ethno-Medical Centre, collected the award, making a touching dedication to his wife, daughter and the 2000 MiMi implementers involved in the project.

## ROUND-UP OF THE EHFG 2015 CONFERENCE

Helmut Brand, President of the International Forum Gastein, then took the stage to recount key points from the past few days in his conference round-up. Brand covered the following points:

- Cross-border care needs sincere cooperation and joint procurement.
- We need to consider the costs and consequences of not supporting non-EU countries.
- The Lisbon Treaty does not stop us from doing more if we wish to do more.
- We need clear leadership and a balance between the EU and technology.
- Health is a political choice.
- A state of crisis is the new normal, in one form or another, we have been in “crisis” for the past 10 years.
- There need to be closer links between health and social services.
- The availability and accessibility of EU funds needs to be improved; there is scope to make use of them through the European Semester.
- We need to remember and respect the core values of the EU, improve information for citizens, particularly with regard to cross-border care, and increase the level of health literacy generally in the population.



Ingo Raimon (FOPI), EHA Winner 2015 - MiMi Project - Ramazan Salman, Helmut Brand and Peter Brosch (Ministry of Health, Austria)

## HIGH-LEVEL DEBATE

The second part of the plenary consisted of a two part high-level debate, firstly exploring the panel's views and secondly those of the audience. David Rose opened the debate by asking the panel to present their views on specific questions. Vytenis Andriukaitis, EU Commissioner for Health and Food Safety kicked off the debate by outlining his current and future priorities advocating for a change of paradigm towards more and better public health. Health is the most precious resource and by improving health literacy, education, access and public spaces where people can exercise, productive economies will grow. Andriukaitis expressed that he felt like a “Young Gasteiner”, sharing his belief that greater involvement of young health professionals and NGOs was essential to improve public health in the long run, with “prevention, promotion, protection and participation” being the key to success.

According to Guenael Rodier, Director of the Division of Communicable Diseases, Health Security and Environment, WHO Regional Office for Europe, crises are caused by the lack of preparedness of our health systems. He drew attention to the fact that the current moment offers lessons to be learned, stating that “We need to capitalise on the momentum of the Ebola crisis”. His message was clear, if Europe and other stakeholders want to improve health security on an international and national level, we need to be aware of our vulnerabilities and start investing in prevention and capacity-building, instead of just plugging the holes in times of emergencies.



When asked about how to achieve the best healthcare in the EU, Lydia Mutsch, Minister of Health, Luxembourg, which currently boasts this achievement, drew a positive picture of her country's healthcare system. With universal health coverage, a comprehensive benefits package and national action plans for cancer and dementia, Luxembourg benefits from the fact that it is a small country with strong financial resources. But these self-evident facts alone could not explain the positive balance, Mutsch argued. In her view, the true success of Luxembourg was to maintain a high investment in prevention at the time of the economic crisis, when other Member States made cuts.

Guntis Belevics, Minister of Health from Latvia, was much more nuanced when it came to the distance covered so far by his country and the challenges lying ahead. Latvian patients still have to face high co-payments and increasing prices for innovative medicines. Fighting parallel trading and reducing patients' spending will be among the next priorities of his Ministry, along with the implementation of e-health projects.

A large section of the debate was dedicated to the burning issue of refugees' health and universal health coverage. Brand noted that the EU had almost achieved universal coverage, before asking: "Can we commit to keep it this way and work towards exporting this model?"

Mutsch stated the need to communicate better to the public on the migrant crisis, stating "the thought that refugees bring diseases needs to be defeated". She welcomed the clear message from the EC and its willingness to solve the problem. She offered the process applied in Luxembourg as an example of best practice, where every new refugee receives medical screening and care, and 95% of them are vaccinated.

Commissioner Andriukaitis then engaged in a very strong intervention on the role of the EU in the refugee crisis, denouncing the reluctance of Europe to take in 100,000 refugees, "We are all migrants on the European continent", he said, deploring the lack of understanding of EU values. Proud of the proactive role of the institution he represents, he underlined the need for the EU to use all the resources it has at its disposal, for example its special legislative and financial instruments.



Lydia Mutsch, Guenal Rodier, Guntis Belevics and Vytenis Andriukaitis

Mainstreaming Health in All Policies was also discussed.

All panellists agreed this was the way forward. Commissioner Andriukaitis reckoned this responsibility was incumbent upon him as far as embedding this concept within the EC was concerned. He stressed the need to encourage horizontal cooperation at national level. Helmut Brand suggested that demographic change be the cross-cutting issue to use when talking to other fields to engage the Health in All Policies conversation.

The Closing Plenary was also the opportunity for Commissioner Andriukaitis to share his priorities for the coming year. Anti-microbial resistance and the use of antibiotics in all sectors and universal coverage of public health preventive measures for older people were among the dossiers mentioned. He also affirmed his intention to contribute to the EU2020 Strategy's employment goals by maintaining a healthy workforce and by promoting employment in the health sector. This sector offers huge opportunities for employment.

Mutsch queried how the EC could support professionals to engage in the health debate, as health should be part of the social discussion in Europe.

# HEALTH CHECK

## HOW HEALTHY ARE EHFG PARTICIPANTS?

### CHECK-UP

This year our participants had the possibility to run a quick and non-invasive health check.

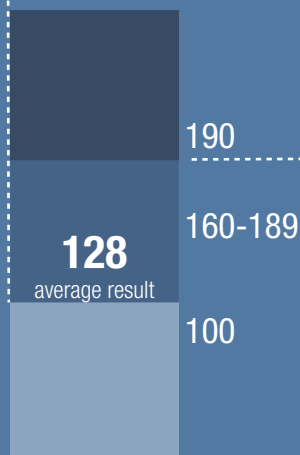
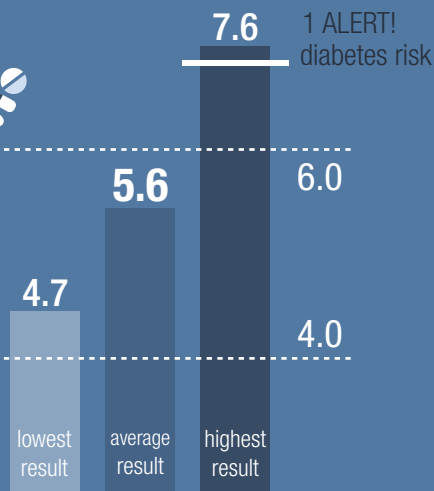
We screened blood sugar measurements and cholesterol levels of 74 Gasteiners - female and male, young and younger - and can state that the EHFG participants are fairly healthy!

### RESULTS

An average EHFG participant has a sugar measurement of 5.6 and slightly increased cholesterol level of 128.

### REMEMBER

Even if you feel fine, you should still do your regular check-ups. This can help you avoid problems in the future!



**BLOOD SUGAR**

**CHOLESTEROL**



# HEALTH SECURITY

FORUM 4  
Global health and health systems  
strengthening.  
Europe and developing countries

FORUM 8  
Securing health.  
Importance of the implementation  
of the International Health  
Regulations (IHR)

LUNCH WORKSHOP 1  
Health threats  
response

part III

# Global health and health systems strengthening

Europe and developing countries

Forum 4 aimed to build awareness of the benefits of the European Union's development cooperation in the field of health and to take a look at the issues and challenges ahead.

The session started with an introduction from Kevin McCarthy, DG International Cooperation and Development of the European Commission (DG DEVCO), European Commission's representative. Topics covered during the forum included health system strengthening and the weaknesses that health systems display, as well as the need to further support universal access to healthcare.

## LEADERSHIP FOR GLOBAL HEALTH

Ilona Kickbusch, Director, Global Health Programme, Graduate Institute of International and Development Studies, set the scene in her keynote speech stating that the starting point of global health system strengthening is leadership. She underlined that the present global health crisis is not primarily one of health but of governance and that the EU would be called upon to be even stronger in taking this leadership role. Leadership could be more determined, more visible and stronger in the area of global health governance especially when it comes to international solidarity.

Five leadership opportunities were presented:

- Sustainable Development Goals (SDGs)
- Universal Health Coverage (UHC) (SDG 3)
- global health security
- people on the move
- multilateralism for health (a global public goods based model).

Right now with the refugee crisis, we are experiencing a cosmopolitan moment, when governments and institutions wake up and decide to do something about it. Another example happened last year during the Ebola crisis, when WHO declared an international public health emergency. This was the point when western countries finally got engaged and listened to the outcry from West African countries and several non-governmental organisations (NGOs) on the ground. In terms of health security, there is no difference between foreign and domestic threats. We have seen in the recent past with Severe Acute Respiratory Syndrome (SARS), the swine flu and Ebola epidemics how global risks tear down national boundaries and jumble together the native with the foreign.



Source: The 2030 Agenda for Sustainable Development and new Sustainable Development Goals adopted on 25 September 2015  
 URL: <https://sustainabledevelopment.un.org/> (15.03.2016)

Kickbusch referred to Ulrich Beck, who speaks about a global risk society and that we moved from a period of stability to a permanent crisis. But our models are not geared for crisis being the new normal. This opens up a global space of threat and a shared global space of responsibility. For example, within the framework of the newly adopted SDGs, the European Union could take on responsibility to speak with one voice and lead the way by implementing universal health coverage, primary healthcare or the WHO Global Strategy for Women and Adolescent health.

## INVESTING IN HEALTH SYSTEMS

Taskin Ur Rahman, Advocacy and Every One Campaign Manager, Save the Children, provided the audience with a perspective from Bangladeshi reality where 64% of healthcare is financed by out of pocket payments and only 16% of child deliveries are performed in facilities, the rest being at home. Although the country has achieved Millennium Development Goals 4 - reduce child mortality - and 5 - improve maternal health - child death rates vary greatly across different regions and the proportion of facility deliveries has not increased as hoped during the last five years. Even in regions where proper facilities are in place, material and human resources are still lacking. "With 160 million inhabitants we have to go bottom up to ensure access to healthcare" Rahman says.

The next speaker, Frazer Goodwin, Senior Advocacy Advisor from Save the Children, demonstrated our global health interdependence using the example of the ongoing Ebola outbreak which has exposed the weaknesses of under-financed and understaffed health systems in these countries.

Weak, under-performing and low-quality healthcare somewhere has a potential to affect everywhere, therefore we need to support health systems globally. The European Parliament echoed this demand when they called for an increase in the European Commission Health Aid budget and a fixed quota of 20% to be allocated for health and education. Nevertheless, the recently adopted budget does not reflect these changes. Goodwin pointed out that external EU actions must go beyond aid and also tackle issues like human resources for health in policy-making, address the 10/90 gap in Research and Development and the need to regulate financial markets.

## UHC & THE RIGHT TO HEALTH: BUOYED OR DROWNING IN SUSTAINABLE DEVELOPMENT?

The next panellist was Remco van de Pas, a Researcher at the Institute of Tropical Medicine in Antwerp, Belgium. He gave a presentation on Institute's report advising the EC on how to move along with the SDGs.

Van de Pas emphasised the leading role of the EU towards UHC and the coherence between the fundamental human right to health and UHC. He concluded that there is a gap between the set goals and the actual member state investments. There is also a deficit in the health workforce investments. There is a current window of opportunity to advance UHC, but political leaders are tending to ignore it, which means it is up to health professionals to deliver the investment required. As a final note, van de Pas raised a warning from the perspective of economic research, referring to Jason Hickels critique of the SDGs<sup>1</sup> as not only a missed opportunity but actively dangerous because they lock the global agenda around a failing economic model.

The session debate touched upon the Transatlantic Trade and Investment Partnership (TTIP). According to Kickbusch, the reason for the mistrust around this issue is the lack of involvement from civil society and the lack of transparency around TTIP negotiations. Stakeholders should have been involved in the process from the start. TTIP will have a significant impact on health which needs to be analysed carefully in the future. "In the 21st century, those kind of negotiations can not be done behind closed doors", she concluded.

One of the crucial questions from the audience asked if the EU has an action plan for the implementation of the SDGs?

McCarthy indicated that topics like health system strengthening and human resources for health are dealt with at the G7/G20 meetings and, as today's discussion has showed, the current SDGs are more political, complex and broader than ever meaning more stakeholders and different actors need to come together and work across policies. He stressed that there is not yet an EU-wide action plan on how to implement the SDGs as they have just been formally adopted, and the EC plans to undertake an internal and external review on how to move forward, which will take some time.

<sup>1</sup> Jason Hickel, Five reasons to think twice about the UN's SDGs  
URL: <http://blogs.lse.ac.uk/africaatlse/2015/09/23/five-reasons-to-think-twice-about-the-uns-sustainable-development-goals/> (15.03.2016)

Global health is first and foremost a governance issue, we need to think about sustainable solutions and overcome our silo-based thinking. Current development activities are highly fragmented as evidenced by the diversity of the Global Fund, the GAVI Alliance and PEPFAR to name a few. These programmes have saved many million of lives and improved treatment for many millions of people but arguably have not focused on the sustainable development of healthcare systems. If we look at the example of Tanzania or Zimbabwe we can see that the more development aid flows in, the less the government spends on healthcare. Goodwin raised the question: “Do we need to rethink the grouping into LIC/MIC/HIC?” Graduating out of each grouping is actually leaving countries behind. In terms of health systems we still think about them in a very technical way, but we also need to take our thinking to a political level and see what political leaders are willing to do.

McCarthy underlined the importance of the strategic priorities of countries receiving aid. There is a risk that ministries of health are not able to take the necessary steps to adequately meet population health needs, due to competition for limited resources by other issues such as defence, security and climate change.

Another remark from the audience agreed with Ilona Kickbusch’s focus on governance. The EU needs to connect their priorities with accountability. Health system strengthening needs governance - that should be our focus. Political commitment is at the core of global health, making the debate more political will be crucial both for donors who want a deeper sense of accountability and for receiving countries.

The main theme of the conference, securing health in Europe, was reflected in the agreement of the panellists that we cannot discuss European health without global health.

Johannes Sommerfeld, Scientist Research Manager from WHO Special Programme for Research and Training in Tropical Diseases concluded: “The bottom line is health is a political choice, global health crisis is a crisis of governance. This requires action from everybody at the level they are working at!”



Johannes Sommerfeld, Jesca Nsungwa-Sabiiti, Aye Mya Aung, Daovieng Douangvichit, Wilm Quentin  
Frazer Goodwin, Pat Mayers, Taskin Rahman

The session also included case studies presented from:

- South Africa by Pat Mayers, Associate Professor, Faculty of Health Sciences, University of Cape Town on strengthening PHC services and thereby healthcare users with an example from the field.
- Uganda by Jesca Nsungwa-Sabiiti, Head of Child Health, Integrated Management of Childhood Illness, Ministry of Health on integrated community case management.
- Laos by Daovieng Douangvichit, Deputy Head of Research Outcome and Management Division, National Institute of Public Health, Ministry of Health on a case study for policy improvement to reduce alcohol consumption.
- Myanmar by Aye Mya Aung, Lecturer, Nutrition and Food Safety Department, University of Public Health, Yangon on an EC project about strengthening public health capacity to respond to Myanmar’s disease transition.
- European Observatory on Health Systems and Policies by Wilm Quentin, Research Fellow, WHO Collaborating Centre for Health Systems Research and Management Berlin University of Technology and Young Forum Gastein Scholar on health system analysis for health system strengthening in Europe and Africa.

■ Written by Charlotte Deogan and Robert Ofner ■

## FORUM 4

Organised by DG International Cooperation and Development (DG DEVCO), European Commission





# PERSON OF THE YEAR

# TIME

## THE EBOLA FIGHTERS

**Dr. Jerry Brown**

The Liberian surgeon, 46, turned his hospital's chapel into the country's first Ebola treatment center

Source:  
© TIME

Photograph by Jackie Nickerson for TIME  
URL: <http://time.com/time-person-of-the-year-history/>  
(15.03.2016)

# Securing health

## Importance of the implementation of the International Health Regulations

### CURRENT STATE AND LESSONS LEARNT

The first part of the Forum aimed to provide an overview of the current state of International Health Regulation implementation and lessons learned from recent major outbreaks.

As first, Ilona Kickbusch, member of the Ebola Interim Assessment Panel (EIAP), presented briefly its recommendations on:

- 1) the World Health Organization's health emergency response capacity;
- 2) the World Health Organization's role and cooperation with the wider health and humanitarian systems areas and
- 3) the International Health Regulations.

Kickbusch's talk focused on the third point. She stressed that the

EIAP emphasised that its analysis of the Ebola crisis needed to be done against the backdrop of a very complex system, including not only WHO, but also the wider UN system and the general context in which Ebola occurred at the Member State level.

Based on the IHR, WHO declared a Public Health Emergency of International Concern (PHEIC) for the Ebola outbreak. There was significant criticism that the PHEIC has been declared too late, also from EIAP's side. However Kickbusch pointed out that the PHEIC declaration does not automatically lead to a functioning response. The EIAP suggested considering the possibility of installing a mechanism prior to announcing a fully-fledged PHEIC.

The EIAP further found that for the Ebola crisis, the IHR instruments

### CORE FUNCTIONS OF THE INTERNATIONAL HEALTH REGULATIONS

In today's connected world, health security is a global issue. We must all protect ourselves, and each other, from threats like infectious diseases, chemical and radiological events. That is why 196 countries have agreed to work together to prevent and respond to public health crises. The agreement is called the International Health Regulations, or IHR (2005), and WHO plays the coordinating role. Through the IHR, WHO keeps countries informed about public health risks, and works with partners to help countries build capacity to detect, report and respond to public health events.



Source: World Health Organization;  
URL: <http://www.who.int/ihr/en/> (15.03.2016)



and processes were not sufficiently used. The IHR should probably be considered to allow alert levels other than just PHEICs, by specifying:

- 1) when should the overall UN system be involved,
- 2) how decisions related to IHR relate to the Security Council, and
- 3) communications between WHO's Director-General and the UN Secretary General.

Member States also have responsibilities in terms of how they finance the WHO, particularly with regards to a contingency fund to support the WHO's emergency response capacity. Kickbusch stated that the WHO should reorganise itself and create a centre for emergency preparedness and response.

A very relevant idea highlighted in this first talk - which was also stressed by the following speakers - was that, despite the suggestion to revisit the International Health Regulations, the truth is that the IHR are not being implemented to their full extent. In regard to the rest of the recommendations given by the EIAP, Kickbusch raised the question of whether there should be incentives and sanctions for (not) following the IHR.

Also related to the IHR, the United Nations Mission for Emergency Ebola Response (UNMEER) might not have been the most successful of enterprises, but it did lead to the political attention needed to tackle this health crisis. The IHR needs to allow for mechanisms to allow political support. Kickbusch ended by stating that due to our system of unsustainable development, Ebola-like outbreaks will be more common in the future.

Next point on the agenda was the overview of the IHR in the European Region and report from the 68th World Health Assembly, delivered by Guénaël Rodier, Director of the Division of Communicable Diseases of the WHO Regional Office for Europe. He highlighted the fact that the IHR (2005) is a legally binding document adopted by the 55 State Parties in the European Region. The initial purpose of the IHR was to give a public health response to the international spread of disease and at the same time avoid unnecessary interference with international traffic and trade. The 2005 IHR regulations included some revolutionary concepts such as "containment at source" or the inclusion of the concept of "public health threats" as opposed to a "static disease risk". It also has a more adaptive nature and proposes context related responses instead of pre-set measures.

At the 68th World Health Assembly (May 2015), lots of issues related to the IHR implementation were raised in connection with the Ebola crisis.

Rodier also gave his view on why the IHR are not being implemented. First, there is simply not enough awareness of its existence by the people in the driver's seat. Secondly, there is a lack of integration with health systems work. Integration will require political will and a higher dedication of resources to the implementation of the IHR. Thirdly, there is insufficient intrasectoral collaboration. Health security involves not only the health sector but also sectors such as animal health, environment, transport or national security. Rodier pointed to the limitations of national self-assessment on the implementation of the IHR. He stressed the need to have more independent evaluations and proposed other options to monitor the implementation of the IHR by nations such as after action reviews and exercises that involve all the players involved in health security.

Philippe Calain, Médecins Sans Frontières (MSF) completed the first part of the discussion by sharing MSF's perspective on health security and the IHR. He explained why MSF is reluctant to join the global surveillance agenda. The IHR recognises that the WHO can take into account reports from multiple sources. As a non-state actor MSF could, in theory, contribute to such event-based reporting. However, Philippe Calain stated that MSF was reluctant to contribute to this events-based reporting for three reasons: 1) the securitisation of public health, 2) community benefits, and 3) health systems.



Outi Kuivasniemi, Philippe Calain, Guénaël Rodier, John F Ryan, Didier Houssin, Ilona Kickbusch

With regards to the first point, he asked whose security and what type of security we are talking about? Calain raised his worries about the semantic shift from response to awareness.

The second group of reasons related to the unclear community benefits. Calain made his point by highlighting how even though the Ebola crisis showed its most brutal effects in West Africa, it is far from clear if related research and innovations are going to benefit these communities or people from industrialised countries. Finally, he explained reasons related to health systems, highlighting the difficulties of implementing health surveillance by field practitioners. He gave a number of reasons such as the redundancy of public health surveillance systems, ambiguity between planning and early warning systems, administrative burdens and lack of feedback, opportunity costs, user fees and responses to outbreaks being delayed and often too invasive. The second part of the forum focused on advancing the European International Health Regulations agenda, including the work done on the European decision on Serious Cross-Border Health Threats and the Global Health Security Agenda.

## ADVANCING THE EUROPEAN IHR AGENDA

John F Ryan, Acting Director, DG for Health and Food Safety (DG SANTE), European Commission, started his presentation by highlighting the role of the Serious Cross-Border Health Threats Decision in IHR implementation. The Decision aims to:

- 1) allow Member States to coordinate their response,
- 2) reinforce preparedness and response planning at EU level,
- 3) improve the joint procurement of medical countermeasures,
- 4) report on surveillance to the European Centre for Disease Prevention and Control (ECDC),
- 5) have a common risk assessment and rules for alert notification.

Ryan stated that simulation exercises are a good mechanism to test inter-sectoral collaboration and preparedness to cross border health threats. Recently, the 28 Member States along with the WHO and the ECDC participated in the “Quicksilver” exercise. The aim was to test, among others, the capacity and capability to provide rapid risk assessment internationally.

In terms of lessons learnt from the Ebola outbreak, some learning points have been identified: it is important to increase international capacity building in Africa and to prepare Europe for a rapid response. In this sense, the IHR processes and implementation need to be discussed to enable it to become a more operational tool.

The issue of trust and enforcement is not a new problem; the EU has spent many years chasing Member States into courts to implement directives. In terms of the IHR, there is no court where countries can be chased. Sanctions are an interesting idea to support the implementation of the IHR, but this is currently not feasible unless the IHR are changed. A different challenge is the lack of involvement of non-state sectors into the IHR, with the consequences of not having important stakeholders like pharmaceutical companies or the NGO community involved. These weaknesses, intrinsic to the IHR, demand the improvement of IHR mechanisms gradually.

Ryan concluded his presentation with a remarkable statement: the European Commission recognises the huge impact of health threats on the economy and general capacity of healthcare systems of Member States. The IHR go beyond the protection of human health, having an important role supporting the function of the world economy. It is our responsibility to raise awareness about the IHR outside of the health sector.



Source: John F Ryan, The work on the Decision on Serious Cross-Border Health Threats (Power Point Presentation, October 2015)

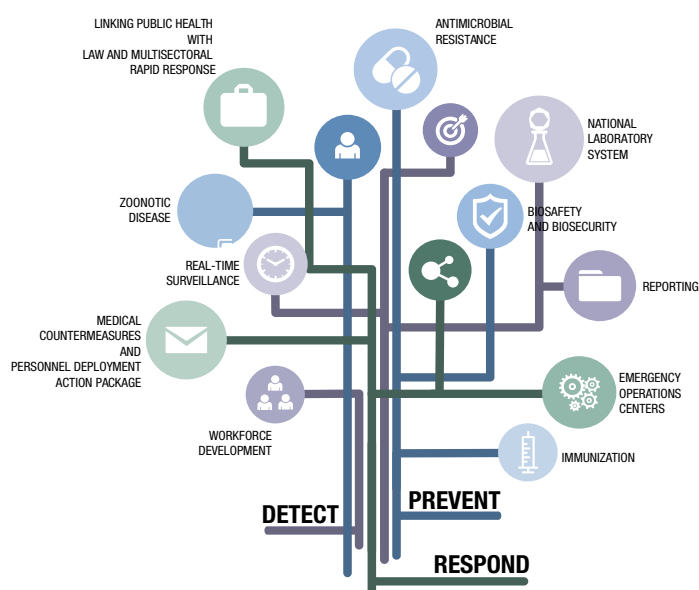
During a meeting in Helsinki, Finland, in early 2014, Member Countries identified eleven discrete GHSA Action Packages, which were discussed further (...). Technical experts from countries around the world worked collaboratively to shape these Action Packages and continue to lead and implement them. The 11 Action Packages have been agreed upon by all GHSA countries. In developing these Action Packages, the goal has been to translate political support into action and to guide countries toward achieving the GHSA targets.

All GHSA Member Countries participate in one or more Action Packages and may choose to fulfill this commitment by building capacity at a national, regional, and/or global level.

Each Action Package includes a 5-year target, an indicator (or indicators) by which to measure progress, and lists of baseline assessment, planning, monitoring, and evaluation activities to support successful implementation.

Source: Global Health Security Agenda  
 URL: <https://ghsagenda.org/packages.html> (15.03.2016)

## GLOBAL HEALTH SECURITY AGENDA ACTION PACKAGES



## GLOBAL HEALTH SECURITY AGENDA

The last presentation was given by Outi Kuivasniemi, Deputy Director of International Affairs at the Ministry of Social Affairs and Health of Finland, concerning the Global Health Security Agenda (GSHA).

The GSHA is a cooperative forum of 50 countries and international organisations operating on a voluntary basis, launched in February 2014. It aims to improve national preparedness and health systems' functional capacity in order to combat infectious diseases, with an emphasis on cross-sectoral cooperation.

All countries must have in place the core capacities required by the IHR. Unfortunately, the current system of self-reporting on IHR capacities at the country-level is not robust.

The WHO Europe Director-General made a strong commitment to the development of a system of external assessment of the IHR core capacities during the last Regional Committee Meeting of the WHO Regional Office for Europe. Cross-sectoral cooperation can be improved with the help of external assessment. GSHA provides a model for voluntary external country assessment and has been successfully tested in five countries. The GSHA strongly supports a shift towards objective external assessment of the IHR.

Kuivasniemi concluded by highlighting some lessons from Finland regarding external assessment. The key points emphasised were country ownership combined with political will, good planning and collaboration with partners.

■ Written by Juan Hoyos and Esther Vizcaino ■

## FORUM 8

Organised by World Health Organization

Regional Office for Europe



# Health threats response

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The European Centre for Disease Prevention and Control (ECDC), in cooperation with the DG for Health and Food Safety (DG SANTE) of the European Commission, hosted a workshop asking "Are we in the EU prepared to respond to the next public health emergency?" The session identified existing gaps and explored what needs to be strengthened or further developed in order to effectively respond to public health emergencies.

Herta Adam, Deputy Head of the Health Threats Unit in the DG SANTE began her presentation by summarising that we have solid provisions in place to manage health emergencies caused by communicable diseases and other serious cross-border health threats in the European Union. The main pillars of a legal framework of Decision 1082/2013/EU on Serious Cross-Border Threats to Health are:

- Threats from communicable diseases, AMR, healthcare associated infections, biotoxin, chemical and environmental events
- Preparedness and response planning at EU level
- Voluntary mechanisms for Member States to jointly procure medical countermeasures, e.g. vaccines, personal protective equipment preparedness
- Permanent epidemiological surveillance of communicable diseases, AMR and healthcare associated infections
- Early Warning and Response System and rules for alert notification to inform the MS, WHO, relevant other alert systems (IT tool)

Lessons learned from the Ebola outbreak can help us to better prepare for future emergencies:

- Provide information for travellers
- Provide key media messages in all official EU languages
- Undertake a survey to assess the state of preparedness in EU Member States
- Prepare guidance on procedures for airports and public health authorities
- Have an EU case definition for reporting cases at EU level
- Provide information on infection control in hospital settings and on personal protective equipment
- Identify treatment and management capacity: around 50 treatment centres have been identified across the EU and a network of specialised laboratories put in place
- Exchange information through clinical networks
- Maintain trade and transport links: this provides the opportunity for healthcare workers to combat the epidemic on the ground in the affected countries
- Prioritise inter-sectoral collaboration: for example to facilitate medical evacuation

The same lessons, tools and principles are relevant for other threats: Polio, MERS CoV, vaccine shortages.



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The first reported case in the Ebola outbreak that ravaged west Africa over the course of the last two years dates back to December 2013, in Guéckédou, a forested area of Guinea near the border with Liberia and Sierra Leone.

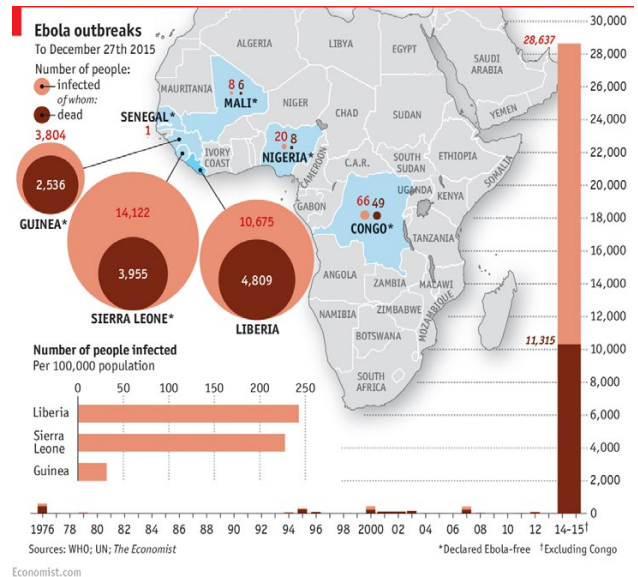
Travellers took it across the borders: by late March 2014, Liberia had reported eight suspected cases and Sierra Leone six.

By the end of June that same year 759 people had been infected and 467 people had died from the disease, making this the worst ever Ebola outbreak.

As of December 20th 2015, 28,637 cases and 11,315 deaths had been reported worldwide, the vast majority of them in these same three countries.

Source: The Economist.

Ebola in graphics. The toll of a tragedy; Dec 30th 2015, 19:47 by The Data Team  
 URL: <http://www.economist.com/blogs/graphicdetail/2015/12/ebola-graphics>  
 (15.03.2016)



A number of issues were identified where there is room for improvement to prepare the EU better for similar crises:

- Strengthen cooperation between sectors involved in health crisis response e.g. between public health, humanitarian aid, development, civil protection
- Support further implementation of the core capacities under the International Health Regulations
- Strengthen the coordination within the Health Security Committee
- Strengthen links between research on preparedness, and public health response

### “THE TIME TO REPAIR THE ROOF IS WHEN THE SUN IS SHINING”

Massimo Ciotti, Deputy Head of Unit, Public Health Capacity and Communication, ECDC, tried to answer two key questions in his presentation: Are we prepared? How would we know? Public health systems across Europe need to be prepared for a naturally occurring outbreak or deliberate release, where we need to:

- quickly recognise the disease (e.g. anthrax, pandemic flu);
- control its spread using isolation,
- quarantine and vaccination;
- ensure that people get needed care;
- coordinate with national and international agencies and
- prevent mass panic.

Public health systems will also need to be prepared for other health emergencies, e.g. such as those of environmental or technological origin such as floods, earthquakes, chemical spills, radio-nuclear incidents or extreme weather.

The main challenges will be coordinating action across sectors and boundaries, investment in the workforce and building the resilience to adapt to the unexpected.

ECDC Preparedness Strategic objectives 2014-2020:

- Evaluate Public Health Emergency Preparedness and address gaps and needs
- Develop tools in support of the implementation of Decision 1082
- Support the exchange of knowledge and practice, and provide capacity building to Member States

ECDC activities in the context of the Ebola outbreak in West Africa were also presented:

- Epidemic intelligence
- Rapid risk assessment
- Weekly Epidemiological updates
- Daily monitoring
- Weekly teleconference with the European Commission
- Weekly video-conference with the World Health Organization
- Deployment under Global Outbreak Alert and Response Network (GOARN): 93 experts; during outbreaks, the GOARN ensures that the right technical expertise and skills are on the ground where and when they are needed most.

In order to assess whether are prepared for the next public health emergency, we must learn from previous emergencies as well as assess existing gaps in preparedness, for example quality improvement within and across public health systems, the generation of evidence to connect capacities and capabilities, and how to measure our ability to respond to the unexpected.

Raed Arafat, State Secretary, Head of Department of Emergency Situations from the Ministry of Internal Affairs, Romania, shared his experiences on how to deal with a public health emergency like Ebola.

Under the National Emergency Commission of Romania, an Ebola committee was created, acting under the direct command of the Ministry of Internal Affairs, and coordinating medical and non-medical services. Following all the recommendations from WHO and ECDC, written protocols were produced and one hospital was fully prepared to harbour all the suspected cases. Border controls were intensified. All people coming from infected areas were identified and followed up. Fortunately, no cases of Ebola were identified in Romania. This experience showed the need for emergency committees to have sufficient authority to take urgent decisions on selected matters without the need to wait for the approval of certain measures from the government or parliament. As Arafat stated, “urgent does not have the same meaning for everyone. For some it may be a matter of hours, while for others it may involve weeks”. Finally, emphasis was placed on how emergency preparedness services should never be externalised, but should be the direct responsibility of the government of the nation.

## EBOLA - THE SPANISH EXPERIENCE

The first case of Ebola outside Africa occurred in Spain. Unlike other countries, Spain did not maintain business or institutional relations with the affected areas in West Africa, however it had sent missionaries there. As Fernando Simón Soria, Member of the Health Security Committee, Ministry of Health, Social Services and Equality of Spain explained, the chances of Spain having to deal with Ebola were extremely low. Nevertheless, the first version of a suspected Ebola cases response protocol was developed in April 2014, the coordination with scientific societies was settled and the border health control was prepared.



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The Ebola crisis showed the need to develop appropriate communication policies for both health workers and the general population.

Fernando Simón Soria,  
Ministry of Health, Social Services and Equality, Spain

Two patients had been evacuated from West Africa and repatriated back to Spain for treatment. On the 6th October 2015, a health worker exposed to the second of these patients became the first secondary case of Ebola outside Africa. At that moment, Spain faced one of its biggest crises and the response provides some lessons to be learnt.

First, the ratio of health workers to patients in Spain is completely different to Africa. In parts of West Africa there may be one healthcare worker for every 40 patients; a ratio much higher than found in the global north. This presents significant workload pressures, which are exacerbated in a state of emergency such as Ebola. The safety of health professionals must therefore be a core issue when dealing with this kind of emergency.

Secondly, if anything characterised the Ebola crisis in Spain it was that the social perception did not correlate with the real risks: while in Africa there were 28,468 cases causing 11,298 deaths, in the rest of the world there were three secondary cases with no deaths. And yet there was an excessive media impact that caused social insecurity and distrust. The Ebola crisis therefore showed the need to develop appropriate communication policies for both health workers and the general population.

## WEAKNESSES REVEALED

Ebola revealed some of the weaknesses of the International Health Regulations. Although Guénaél Rodier, Director of the Division of Communicable Diseases, Health Security and Environment, WHO Europe, thinks that there is no need for any change or update of the IHR, the problem remains that they are not being applied well. First, the IHR are not well known, and are not well integrated within all the national health systems. There is a lack of political commitment to do it. The IHR needs strong inter-sectoral collaboration between the health security sector and the environment sector (an all-hazards approach for climate change, chemical incidents, etc.), the animal health sector (the one health initiative is covering this issue), the transport sector (a clear scope for the IHR) and also with the national security sector, which has proven to be an extremely difficult and very sensitive area. In fact, some of the recommendations were not followed by all the countries, since, for example, some decided to apply some medical controls on their borders that were not advised by WHO. After this experience, there is a degree of consensus that Europe can successfully deal with health emergencies: there is adequate infrastructure, adequate resources and the commitment of inter-sectoral collaboration. But learning from the experiences discussed, we have to respond earlier, be more united and develop better public communication strategies.

■ Written by Sonia Fernández and Karolis Lebednikas ■

## LUNCH WORKSHOP 1

Organised by the European Centre for Disease  
Prevention and Control (ECDC)  
in cooperation with  
DG Health and Food Safety (DG SANTE),  
Health Threats Unit, European Commission





PATIENTS  
AND  
HEALTH  
SYSTEMS

WORKSHOP 1  
Healthy ageing of workers

WORKSHOP 2  
Financing of NCDs

WORKSHOP 3  
Mental health

WORKSHOP 6  
From citizen to citizen

FORUM 2  
Facing multimorbidity:  
Challenges and responses

LUNCH  
WORKSHOP 3  
Workforce skill-mix

FORUM 3  
Implementation  
of comprehensive  
primary care

LUNCH  
WORKSHOP 4  
Empowerment in practice

FORUM 5  
Health information.  
Creating evidence  
for European Union  
health policies

part III

# Facing multimorbidity:

## Challenges and responses

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In the first part of the forum session, the following questions were raised: What do we know about multimorbidity and what do we do? The second part focused on discussing our performance in adapting our health and social systems to the challenges of multimorbid people. The session was facilitated by Boris Azaïs, Director Public Policy Europe and Canada, MSD and Matthias Wismar, Senior Health Policy Analyst, European Observatory on Health Systems and Policies.

### WHAT DO WE KNOW? WHAT DO WE DO?

The session was opened with the statement that “multimorbidity is the most common chronic disease”. Martin Seychell, Deputy Director General of DG Health and Food Safety, European Commission, underlined that multimorbidity is becoming the norm rather than an exception. This is a great challenge because of the impact on peoples’ lives, the expenditures in public health and the sustainability of the healthcare system as a whole. How should we move forward? Around 50 million people, or more, in Europe suffer from multimorbidity. Despite the increasing numbers of patients with two or more chronic conditions, the delivery of care is usually built around single diseases. Health systems in Europe are disease-oriented, while multimorbidity is asking for patient-centred healthcare and a holistic approach. Martin Seychell stressed that something needed to happen. The approach of the EC is to raise awareness and to create a sense of urgency.

Further, the problem should be addressed collectively by bringing stakeholders together that have not been collaborating in the past. The approach of looking at this growing health problem should change from a single chronic disease perspective towards an agenda which addresses how one chronic disease manifests into multiple conditions. Putting this issue in the centre of the EU public health agenda will mark a milestone in policy making. Several EC projects contribute to the multimorbidity agenda: the innovative partnership on integrated care; I Care For You; the CHRODIS Joint Action Programme; and health system performance assessment.

Rokas Navickas from the CHRODIS Joint Action Programme, Vilnius University Hospital, Lithuania, started by asking the following questions: Is multimorbidity really something new? Chronic diseases are a challenge that have benefited from a lot of attention and financing, but why are we not succeeding at addressing them more effectively? Multimorbidity is a big part of health expenditure but it has not been researched much. Clinical trials exclude multimorbid patients because the topic is too complex, which results in a lack of data on multimorbid patients. Research has been done on which diseases exist together, however not on the possible root causes of developing one after the other. What is known is that multimorbidity causes longer hospital stays, more frequent hospital visits and premature death.

The most expensive group of patients is changing from 65 plus to 40-50 year-olds. One out of every five Americans is multimorbid.

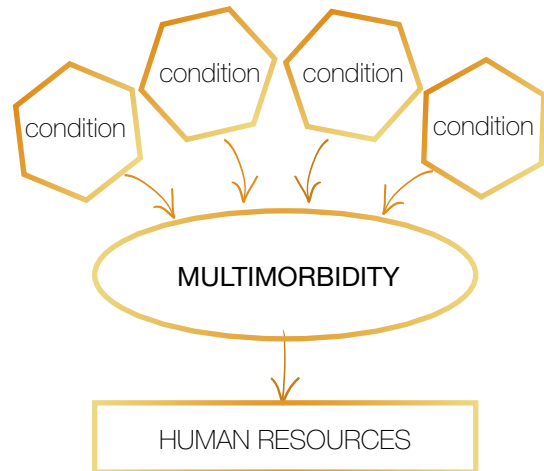


The associated costs of all expenditures in the USA is estimated at 78%. This is not only a problem for the health system but also, and especially, for the patients. Multimorbid patients suffer more, use multiple drugs with possible side effects and have a poor quality of life because of their condition.

To act on the rising problem of multimorbidity we could anticipate which disease the patient is going to develop next. For this matter more research needs to be done on how we can prevent the next chronic disease from developing. To answer this question a shift needs to be made from a vertical mono-morbid approach to a horizontal co-morbid approach. To realise this, several interventions are needed: a professional intervention, as well as a financial, an organisational and a structural intervention. Professionals need to be educated to exercise a horizontal approach. Furthermore, it is an opportunity to broaden the guidelines from solo diseases concentrated on identifying the key disease to describing the risk factors and possible other diseases.

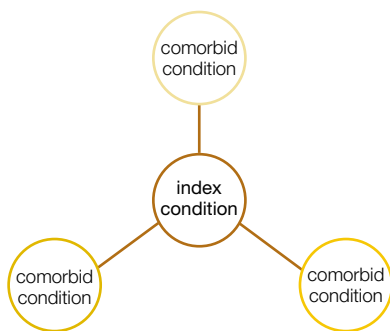
## SHIFTING PARADIGM

from vertical/mono-morbid interventions  
to comorbidity and multimorbidity approaches enhances effectiveness and efficiency of human resources utilization



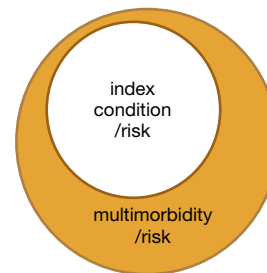
Source: Rokas Navickas, Multimorbidity Is it really something new? (Power Point Presentation, October 2015)

A



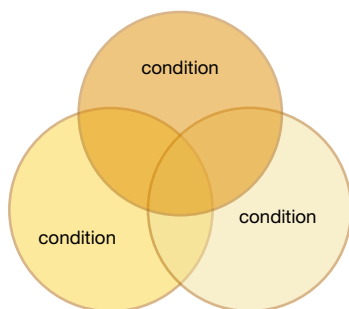
A guideline may focus on an index condition, and choose to address some number of comorbid (coexisting) conditions, or comorbidities.

B



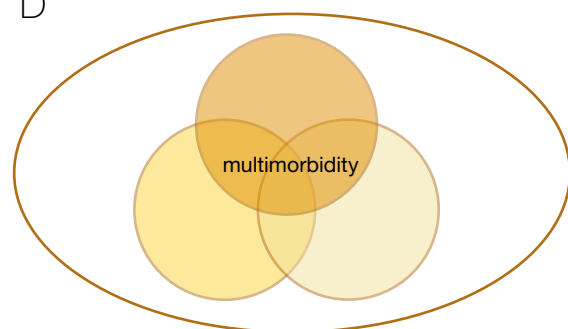
A guideline may focus on an index condition, or risk factor, and may choose to address how some marker of overall morbidity affects the management of the index condition. For example, the guideline may focus on diabetes, but may discuss how management would change in people with varying degrees of morbidity or mortality risk or other risk.

C



A guideline may focus on a specific combination of conditions - where all (two conditions, three conditions, or more) are specified. An example is a guideline on the management of people with HIV and chronic kidney disease.

D



A guideline may focus on multimorbidity, or its consequences. Examples may include a guideline focused on care coordination for multimorbid patients, or a guideline focused on polypharmacy or falls. Guidelines may use more than one of the above approaches, within the same guideline.

Source: Katrin Uhlig, Bruce Leff, David Kent and all. A Framework for Crafting Clinical Practice Guidelines that are Relevant to the Care and Management of People with Multimorbidity. J Gen Intern Med. 2014 Apr; 29(4): 670-679. Rokas Navickas, Multimorbidity Is it really something new? (Power Point Presentation, October 2015)

In answer to the question whether we should put a focus on multimorbidity in our policies, Vesna-Kerstin Petric from the Ministry of Health in Slovenia replied that in her opinion this was not really necessary. In general she thought the priority was to invest in prevention and integrated care, patient empowerment and coordinated care. For both multimorbid patients and patients with chronic diseases, coordination and integration of services is one of the most important points to address in healthcare systems, especially with the social sector. In Slovenia this is specifically the responsibility of the primary healthcare system, which has invested in training registered nurses to help the patient through the system.

Andrea Feigl, Harvard T.H. Chan School of Public Health, USA, raised the issue about the availability of data. Even in high-income countries there is not much data available regarding the cost-effectiveness of integrated care. Multimorbidity causes high expenditure but because of the lack of data it is not clear if integrated care is the answer. One recent study, including an RCT focusing on integrated care vs. conventional (disease specific) primary care, found that the health outcomes of the patients in integrated care were better; there was an increased quality of life and lower average outpatient healthcare costs compared with patients receiving usual care. A similar research project is ongoing in Europe.

### MANY DISEASES, ONE CARE?

In the second part of the forum, Tit Albreht, project coordinator of the CANCUN (Cancer) Joint Action Programme, National Institute of Public Health in Slovenia, began by emphasising that we manage to transform acute diseases into chronic diseases because of medicines and care. This is of course a very positive development but it also leads to patients being multimorbid more often. Albreht underlined that prevention and good management of chronic diseases and multiple chronic diseases is becoming increasingly important. Research shows that the increase in needs is exponential and not linear for a person with one chronic disease who develops another one. There are some opportunities to assess these needs for people with multimorbidity. The first opportunity is a greater role for primary care as an entry point, although this might not be appropriate for all healthcare systems' contexts. Furthermore, flexibility in organising care is needed.

This includes support for patients in terms of daily living and social support. Finally, developing comprehensive patient pathways, in assisting both patients and professionals, is something that should contribute to a smoother and more efficient process.

Francois Schellevis, Head of Research at the Netherlands Institute for Health Services Research, underlined that multimorbidity is very different from having one single chronic disease. The 'spaghetti model' of care shows that the care of patients with three or more chronic diseases is very complicated. This model was the starting point of the 'I Care For You' project, which mapped the existing policies and programmes for people with multimorbidity in the EU. A striking preliminary result was that they found zero member states with a national policy on managing patients with multimorbidity. However, 101 programmes in five EU countries deal with multimorbid patients, with however only two at a national level. These programmes mainly focus on increasing multidisciplinary collaboration, improving coordination of care and patient involvement. The majority of these programmes were of good quality and had a good chance of being implemented. The conclusion is that on a regional level, in the field, there is a lot of promising experience. Therefore, we have to work at both levels. At a national level we need to formulate policies on how to deal with patients with multimorbidity, on a regional level, we should continue with the experiments, project programmes and evaluations to show that it is feasible and doable to increase collaboration, coordination and patient involvement.

Mariana Dyakova, Consultant in Public Health, at the University of Warwick in the UK, was also involved in the 'I care For You' project. Of the 101 programmes targeting patients with multimorbidity, two thirds were small scale, had a very specific target group or involved only a limited number of disciplines, one third was much more comprehensive. Dyakova described eight best practices as to how these programmes were implemented in the field. An important conclusion was that there was no perfect programme or a one-size-fits-all example. Programmes need to be adapted to the local context.

Stephan Vandenbroucke, Professor of Health Psychology, Catholic University Leuven in Belgium, underlined the importance of health literacy, and specifically self-management education in single diseases as for example diabetes, but also in multimorbid patients.

The Diabetic Health Literacy Project was started to investigate which programmes were available for self-management in Europe and what was the effectiveness of the programmes. Although this study was especially designed for patients with diabetes, he argued that the results could be extended to patients with multimorbidity. In their study they found a very wide variety and range of programmes for self-management education available in Europe. A common problem, though, was that many of these programmes did not reach the people in need. A clinical study found that overall the programmes were effective in improving important behavioural outcomes (e.g. foot care and diet) and that it did not matter which type of programme was followed (e.g. group vs. individual programmes). The overall costs of these programmes were extremely limited (+/- 150 Euro per patient). Ultimately we should use existing programmes, rather than invest in developing new ones, make them accessible for patients, and adapt them to the cultural context and to the educational level of patients.

Following a question from the audience about the role of shared decision-making in the treatment of multimorbid patients, the whole panel underlined its importance. Tit Albrecht emphasised, however, that only patients with good health literacy can engage in joined decision-making.

The panel concluded that not only patients but also health professionals need training in shared decision-making. Furthermore, the panel and the audience discussed the topic of who was in charge of managing these patients? As heard in the first part of the forum session, multimorbid patients see around fifteen different specialists. From the 'I Care for You' project they learned that a case manager is needed. This can be a volunteer, a family member or a nurse, as long as there is one central point of contact or person who can assist the patient in navigating their way through the healthcare system. In short, putting the patients in the driver's seat is key, and there are a variety of existing projects waiting to be scaled up or emulated.

■ Written by Laura Cloostermans and Damiët Onderstal ■

## FORUM 2

Organised by International Forum Gastein and supported by an unrestricted educational grant from MSD



# Facing multimorbidity:

## Challenges and responses

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Multimorbidities are multi-challenging for patients as well as for healthcare professionals. As populations within Europe get older and rapid medical developments result in longer life expectancy, a higher prevalence of non-communicable diseases (NCDs) can be seen. The topic of Forum 2, Session 2 was “Addressing multimorbidity to improve sustainability”, and was co-moderated by Boris Azais, Director Public Policy Europe and Canada, MSD and Matthias Wismar, Senior Health Policy Analyst, European Observatory on Health Systems and Policies. Pathways for managing NCDs were debated, from both structural and economic perspectives. A number of models for these pathways have been developed, however these must be adapted to fit the different cultural aspects of different healthcare systems across Europe, in order to ensure sustainability. Session participants agreed that additional investments in health and social systems were required.

### ADDRESSING MULTIMORBIDITY TO IMPROVE SUSTAINABILITY

An example pathway development for managing NCDs was given by Manuel García-Goñi, Associate Professor, Department of Applied Economics II, Universidad Complutense de Madrid. In Spain, the first steps towards the implementation of a chronic care-focused system were made in the Basque country. Within the region of 2.3 million people, patients with comorbidities account for approximately one quarter of all healthcare “users”,

however they account for over 60% of the healthcare expenditure. With an ageing population and increasing prevalence of non-communicable diseases (e.g. cardiovascular diseases, diabetes, obesity) healthcare costs are expected to rise, which invited reform to move towards a more patient-centred, cost effective healthcare delivery model.

The reform began first by estimating the magnitude of the problem (ref. Orueta, J.F., 2014), and second, by re-organising the delivery of healthcare in the region towards more active case management of patients with NCDs. It is evident that efficient management of patients with multiple diseases can reduce use of specialist resources and hospitalisations, thus decreasing overall healthcare expenditure, as well as increasing patients' quality of life. Key attributes contributing to the ongoing success of the model were the transparent payment mechanism and sharing of information with patients.

Several models implemented in other countries have showed the advantages and difficulties of implementing healthcare systems focused on chronic disease care. In Spain the national healthcare system has been evaluated using Ham's model's 10 criteria. The evaluation revealed that: the basic healthcare services are universally covered in Spain; most of the regional healthcare systems rely on primary healthcare; all use electronic health information systems on centralised and decentralised platforms and several regions increasingly involve patients in self-management

through the expert patients programme and schools for patients. The best place for meeting the needs of patients with comorbidities is the primary healthcare setting. Patients prefer this as they can remain close to home. This is also the more efficient place to meet patients' needs, as it focuses on early detection, early treatment and prevention of disease. Unfortunately the primary healthcare setting is under-resourced in Spain due to an absence of a co-payment system in primary and specialist care as well as hospital inpatient care. Similar structural issues, pitted against the pressures of growing demand, can be seen in other European countries.

Changes and improvements are needed to increase the role and responsibility of community nurses and “case managers” in NCD management. This could improve teamwork at the primary care level, coordination between healthcare authorities and coordination between health and social care, for instance through sharing and disseminating best practice. An increased role for community nurses is common in primary care in Spain and has been implemented in several hospitals across the country. Following the national health system evaluation, the Spanish National Chronicity Strategy has been implemented to form the basis for further reform.

Following a discussion on how to finance healthcare reform, Christoph Schwierz DG Economic and Financial Affairs (DG ECFIN), European Commission (EC) pointed out that, in order to meet

exponentially increasing costs in healthcare, a very sound case has to be put to the Ministry of Finance. However, there is a lack of systematic data available to make such a case. It has been suggested that fiscal sustainability has to be reached in Member States in order to meet financial challenges related to reform towards chronic care-focused healthcare systems.

The EC has been urged to invest in prevention, arguably the best measure to tackle the burden of morbidity. It was raised that privatisation could be one way to drive out efficiencies through investment in prevention, however we must be careful that any pursuit of efficiencies does not impact unduely on quality performance. Many countries are using prospective financing to fund healthcare reforms. Public and private partnerships are in demand and the EC has an expert group to evaluate these opportunities. It was expressed, though, that country-specific recommendations should cover collaboration between social care and healthcare.

In light of the growing number and changing nature of patients, the patient voice must be increased in decision-making, both locally and at senior levels. The EC urges patient groups to collaborate with each other and be more proactive in communicating with the EC. A collective voice of disease-specific patient organisations should be represented at the EC. It was pointed out that patient groups do not have a legislative background that defines their role. Nonetheless, existing patient organisations have grown into independent, empowered and transparent organisations.

## TEN CHARACTERISTICS OF A HIGH-PERFORMING CHRONIC CARE SYSTEM (HAM 2010)

- |   |  |  |
|---|--|--|
| 1 Ensuring universal coverage   | 6 Population management is emphasised through the use of tools to stratify people with chronic diseases according to their risk and offering support commensurate with this risk | 8 The need to exploit the potential benefits of information technology in improving chronic care   |
| 2 Provision of care that is free at the point of use  |  | 9 Care is effectively coordinated  |
| 3 Delivery system should focus on the prevention of ill health  | 7 Care should be integrated to enable primary healthcare teams to access specialist advice and support when needed   | 10 Link these nine characteristics into a coherent whole as part of a strategic approach to change |
| 4 Priority is given to patients to self-manage their conditions with support from carers and families |  |  |
| 5 Priority is given to primary healthcare   |  |  |

Source: Ham C (2010) The ten characteristics of the high-performing chronic care system, *Health Economics, Policy & Law*, 5, 1, 71-90

## ... AND HOW DO WE MAKE IT WORK FOR THE PATIENT?

A question "... and how do we make it work for the patient?" opened the final part of the session, moderated by John Bowis, Special Advisor for Health and Environmental Policy and a former MEP. With three patient representatives and a representative from the European Parliament, the experiences and the needs of politicians and patients were expressed.

Karin Kadenbach, Member of the European Parliament (S&D, Austria), highlighted that political decisions should be based on best knowledge and be transparent. The diversity in healthcare systems across Europe does not allow for direct comparison of data, which makes decision-making difficult. However, decisions should focus on finding ways to better use available resources rather than cutting them. Active patient empowerment is seen as a tool for that and patient organisations should raise their collaborative voices to the European level.

Bert Aben, representative from GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks-Europe), urged doctors and pharmacists to communicate. Patients are aware of their conditions and how to deal with them. Having several different diseases at the same time means multiple doctor visits and even more medication, but often doctors focus on the treatment of one disease rather than consulting colleagues regarding the other conditions of their patient. This lack of communication leads to additional consultations, a delay in the treatment and inconvenience for the patient.

Luís Mendão, Vice-chair, European AIDS Treatment Group, being an AIDS patient himself and experiencing the side effects of treatment said: "I am alive because of innovation in medicine!" Nonetheless, he pointed out that there is a lack of coordination between health and social care. Comorbidities of communicable diseases, mental health problems, discrimination and stigma occur at earlier ages, however very little is invested in prevention (2% on prevention vs. 80% for treatment in Portugal for example). In addition, sustainable business models are needed as there is no efficiency between pharmaceutical companies - according to Mendão. Patients are willing and could be involved in research development and in the past 10 years an achievement has been made involving specific patient groups in phase 3 trials.

Wolfram Nolte, EuropaColon, Germany is a leader of many patient organisations. Dealing with cancer, removed colon, spinal spinosis and many more diseases he encourages coordination between health and social care. He added that there is no curriculum for "patient advocacy", but patients must be seen at the same level as the pharma industry as such collaboration leads to innovations favourable for patients and industry. At a European level, in order to raise a stronger voice, national patient representatives should be nominated.

Results of the Patient Access Partnership (PACT) study concluded the session. It was stated that, despite different stakeholders' perceptions of secondary healthcare accessibility (not easily accessible according to healthcare providers, and easy accessible according to the pharmacological association), mutual agreement was reached that health has to be adequate, accessible, affordable and appropriate.

■ Written by Ute Linnenkamp and Grazina Rimseliene ■



Bert Aben, Francesca Colombo, Manuel García-Goñi  
Wolfram Nolte, Christoph Schwier, Karin Kadenbach

## FORUM 2

Organised by International Forum Gastein  
supported by an unrestricted educational grant  
from MSD







# Implementing comprehensive primary care

Success stories: from model to practice

Implementing comprehensive primary healthcare (PHC) is key, but how do we get from theory to practice? Since a lot of evidence about best practice is already out there, this session focused on options and challenges around the implementation of primary care. Chaired by Josep Figueras, Director, European Observatory on Health Systems and Policies, the session covered some important implementation issues and an interactive voting tool led to interesting and entertaining results. The following strategies were identified as having the most significant impact on achieving comprehensive primary care and were followed by intense in-depth discussion.

## STRENGTHEN FINANCIAL INCENTIVES

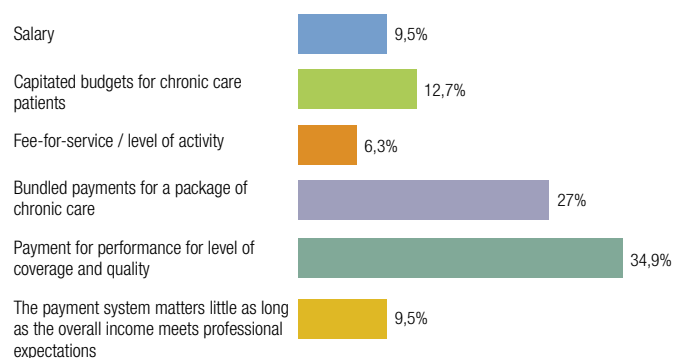
Many participants agreed that payment for performance should be an important part of a payment scheme for comprehensive primary care. However, concerns were raised over how to measure the outcome of coordinated care and over the risks associated with a single-sided focus on providers to meet associated performance targets. Maybe more important than which payment scheme (or mix of payment schemes) to choose, a lot of participants agreed that the first move for a change towards stronger primary care should be to create appropriate financial incentives. You may say extrinsic motivation by financial incentive should be the initiator of a growing intrinsic motivation.

## VOTING RESULTS

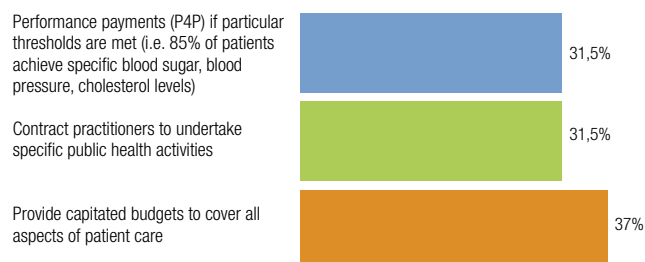
Participants of the forum session were asked to answer several questions relating to the subject of the debate.

To access full voting results please visit our EHFG 2015 archive.

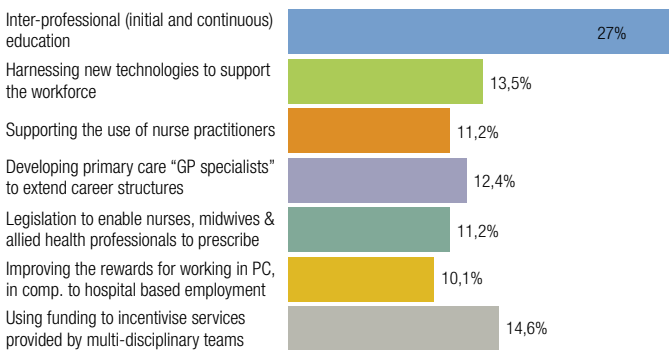
Q5. What is the best payment system to encourage coordinated care in PHC?



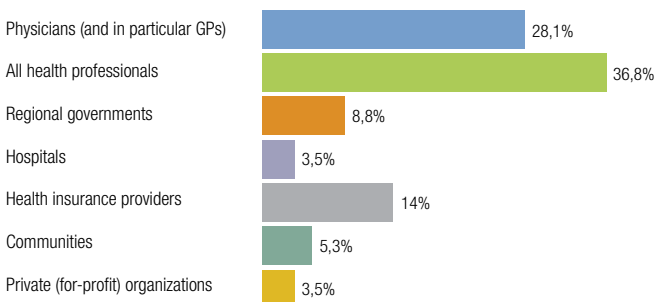
Q6. What is the best payment system to encourage primary care professionals to undertake public health interventions?



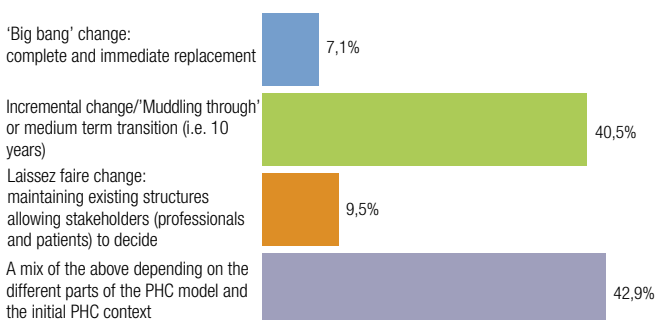
Q8. What are the most important policies to ensure the optimum skill mix in the primary care workforce? Choose two.



Q15. Who are the most important stakeholders in regard to the implementation and subsequent operation of PHC models? Choose two.



Q18. What is the most successful approach to implement a new comprehensive PHC model?



To access full voting results please visit our EHFG 2015 archive.

## APPROPRIATE SKILL LEVELS AND MIX AS WELL AS TRAINING

It was discussed that in countries with a high proportion of isolated GPs like Austria: "It should be normal to work together in federations or networks". In terms of the skill-mix in primary healthcare centres and networks, it is important to make optimal use of health professionals according to the needs of the patient. Medical education and training has to adapt to PHC needs as soon as possible in order to facilitate upcoming changes. In this context an interesting discussion led to criticism on the 'hospitalisation' of medical training.

## REGULATORY FRAMEWORK

Besides a change in the education and training of healthcare professionals, an appropriate regulatory framework was seen as necessary to empower other professions to take on primary healthcare tasks (e.g. health promotion). Further, integrated planning of human resources for primary healthcare is an essential task. Legislation and regulation should always allow for experimentation, innovation and failure. In necessary subsequent evaluations, pitfalls of pilot projects may be discovered but should not be taken as an excuse to not further strengthen primary healthcare. Learning from experience is an essential analytical task.

## IMPLEMENTATION MANAGEMENT

Appropriate management of the reform implementation itself raised the question of whether one 'big bang' could lead to more promising results, or long term incremental change, which may be more prone to changes of direction or unclear and unintended outcome. Some participants with different experiences in the implementation of stronger primary healthcare generally agreed that one big bang followed by a subsequent incremental change may lead to better results. Front-runners in the implementation process also always have to be clear about their role as disruptive leaders (and be strong in disruptive leadership and the subsequent organised process), since the status quo is shaken up and circumstances and conditions of the system are reorganised.

## PLANNING

Mindful planning was seen as important for a strong PHC workforce. In Germany, 30% of students want to become GPs but only 10% eventually do. Most GPs in Austria are not even trained within the PHC setting - they are trained only in the hospital. For some of them, their first working day might be the first time to see a GP office from the inside. Lack of training is also a barrier to involve other health professions, as e.g. ambulatory care nurses or community nurses are not a recognised speciality in many countries.

## STAKEHOLDERS' INVOLVEMENT

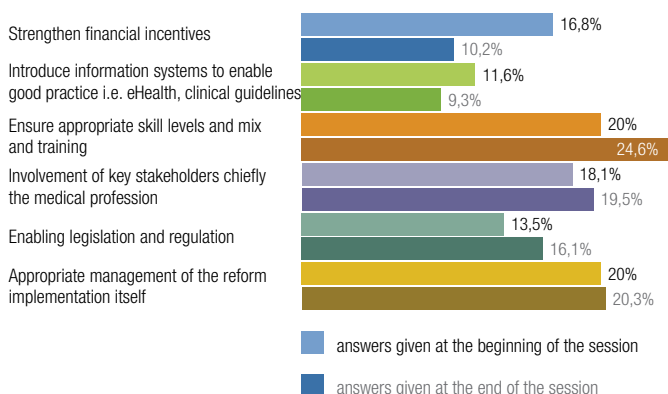
Implementation without the relevant stakeholders seems to be a strange reality in some countries. Talking about a PHC reform (including at this session in Gastein!) without including GPs, nurses, social workers, physiotherapists and patients is not only strange but a huge handicap to successful implementation. It will be difficult to implement a reform if those who should perform it are not involved, are angry, afraid, not interested or not even aware of it. In Austria, it seems to be the case that the healthcare reform tried to start PHC centres all over the country but there are not enough GPs to implement it, many are not aware of the reform, and many don't know what PHC centres are.

## CONCLUSION

To pilot, or not to pilot? This question seems to be connected to the question of having a 'big bang' or making incremental changes and it seems to have similar answers. It depends. Starting with pilots, e.g. experimental PHC centres in Austria, has advantages and disadvantages. Of course, it will be possible to learn from them, to keep the good and to dismiss the bad, but it takes time and meanwhile policy is moving on. Some pilots aren't a healthcare reform, but they might still play an important part within a successful reform. Or are they just an excuse for policy-makers to change nothing?

To sum up, the session went further than well established principles such as the involvement of key stakeholders. Interactive voting helped delegates to better understand the most common challenges regarding the establishment of new primary healthcare centres and networks. Besides some key strategies like education and skill-mix, financial incentives and (not too strong) regulation, the implementation process for primary healthcare should also gain support from the patient via enhanced accessibility and enhanced services. Not only because the patient is the central element in the system, but also because patient buy-in may be one of the best strategies to successfully implement PHC.

Q1./Q19. What are the most important strategies to implement comprehensive PHC reform? Choose three.



Written by Clemens Sigl and Florian Stigler

To access full voting results please visit our EHFG 2015 archive.

## FORUM 3

Organised by Austrian Federal Ministry of Health and Main Association of Austrian Social Security Institutions in cooperation with the European Observatory on Health Systems and Policies



# Health information

Creating evidence for European Union health policies

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Given the main theme of European Health Forum Gastein 2015 - "Securing Health in Europe. Balancing priorities, sharing responsibilities", during a lot of sessions panellists debated and discussed the quality and usability of health data.

The aim of the Thursday evening forum on Health information was to review today's requirements for improving the availability of health information. It was also pertinent that the European Commission is looking to establish a comprehensive and sustainable framework on health information and evidence to improve European Union and international cooperation on the availability of health information for policy and decision-making.

Andrzej Rys, Director in Public Health and Risk Assessment Directorate, DG SANTE, European Commission, introduced participants to the matter of creating evidence for EU health policies. During his presentation he raised a number of questions. Some of them were: what is high scientific information? Can we develop health information systems? Can we produce valuable indicators? How can we report outcomes of our study to policymakers, so they can find it valuable? And how can the EC, World Health Organization and the Organization for Economic Co-operation and Development really work together on such an idea? As a comprehensive health monitoring system is a dream for all of us, it's about time that good minds are put to coming up with the legal and technical solutions.

## NEEDS FOR HEALTH INFORMATION

Rys was followed by Krzysztof Maruszewski, Director of Institute for Health and Consumer Protection, Joint Research Centre (JRC), who noted that actions to address health information challenges at the EU level are harmonisation, collaboration and communication. One of the activities of the JRC in the public health area is keeping cancer and rare disease registries. In Maruszewski's opinion, population based cancer registration is currently impossible, because countries collect data in different ways, so data are incomparable.

Neville Calleja, Director of the Department of Health Information and Research in the Ministry of Malta, presented an example of organisational changes which were caused by a need to increase effectiveness. When in 2011 health ministries in a number of eastern European countries closed down their health information departments, Malta managed to transfer this work, which at the time was found as unproductive and unusable by policy-makers, to an organisation dealing with health intelligence. This organisation changed the way data were gathered and used. They implemented hospital planning, Health Technology Assessments on new drugs, technology and entitlement policies, provided evidence based and target oriented outcomes and worked closely with project team members. They have started to set strategies which included compiling an evidence base, setting targets and health system



performance assessment, and the national health systems strategy for Malta (2014-2020) was launched. Now policy-makers have started to take into consideration the health information/intelligence they are receiving.

Pekka Puska, Director General of the National Institute for Health and Welfare of Finland, gave a presentation on how the national public health institutes are creating evidence for EU health policies. He stated that institutes differ among themselves but their work is sustainable.

Not all the data are gathered in the institutes, there are also registries beyond the institutes, collected in statistical agencies and ministries of health. Health institutes are focusing on the health of the populations and there are particular problems with large population surveys, which is why electronic systems might be used, to reduce costs. What we have to keep in mind is that “political decision-making has its own time and when a decision has to be made the evidence is needed immediately and there are also other driving forces in decision-making than besides evidence, such as ethical considerations”.

Richard Bergström, Director General of the European Federation of Pharmaceutical Industries and Associations, challenged the audience with his point of view - that policy has to also be medicine-oriented. In his opinion, the performance of medicine should be tracked so data would be more valuable. Therefore, regulation which will allow this kind of data collection is needed, he stated. Nowadays, pharmaceutical companies only check the safety and cost-effectiveness of medicines. What seemed controversial to the audience was that when pharmaceutical companies possess this kind of Big Data, it may potentially result in serious consequences on national budgets for drugs reimbursement.

## WAY FORWARD FOR IMPROVING HEALTH INFORMATION AND ITS USE

In the second part of the session the audience had an opportunity to hear how international policy-makers such as the OECD, WHO and EC see future possibilities for health information.

Francesca Colombo, Head of Health Division at the OECD, presented the OECD's ways forward to improve health information

and use. There is little information on morbidity, but good information on expenditure. There is good evidence that chronic diseases and risk factors have a negative impact on market outcomes such as employment probability, wages, labour productivity and early retirement, which result in lost economic productivity (lost income for individuals, lost production and replacement costs for employers, payment of disability benefits). All this points towards a need to make better use of Big Data in health. The four main benefits to better use of big data are: clinical practice improvement, system management, surveillance, research and innovation. The right information on infrastructure will allow data linkages. The OECD set up new data governance, through eight mechanisms, to maximise benefits and minimise risks.

Joao Matias, European Monitoring Centre for Drugs and Drug Abuse, gave a clear example of an indicator on health information - drug use in Europe. The information is used in drug policy and prevention: in prevention messages and campaigns, in policy-making, in policy evaluation.

Herman van Oyen, Leader of the BRIDGE-Health Project, described shortly the aims of the BRIDGE project, which are: developing a framework to understand knowledge-brokering approaches and their interconnections, producing criteria that can be used to assess knowledge-brokering mechanisms and organisational models for knowledge-brokering and undertaking a set of national

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### FOUR MAIN BENEFITS TO BETTER USE OF BIG DATA



**Clinical practice improvement**  
Faster access to critical information  
Improve clinical decision-making  
Coordinate care across settings



**System management**  
Monitor care quality  
Improve technical and allocative efficiency  
Reduce waste



**Surveillance**  
Faster detection and response to public health emergency  
Monitor performance  
Inform policy



**Research & Innovation**  
Statistical power  
Vast and varied datasets  
Better “real world” sampling

Source: Francesca Colombo, Ways forward to Improve health information and use (Power Point Presentation, October 2015)

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case studies that explore further the contextual factors that support the brokering of research into policy-making.

Stefan Schreck, Head of Unit of Health Information and Scientific Committees, DG SANTE, recalled that the EC is directly involved in policy-making, by trying to help Member States to develop their policy-making and by making an impact on the organisations which collect the data. Both the type of data and the presentation of this data differs for researchers and policymakers. Policy-makers need the right information in the right format at the right time.

Tim Nguyen, Unit Leader at the WHO Regional Office for Europe, quickly agreed and assured all that WHO, EC and OECD will still work together, to provide health information that is appropriate to use. This cooperation was stated in this year's Vilnius declaration, which is a continuation of the Moscow declaration from 2010.

■ Written by Ewa Nieckarz and Natalia Żylińska-Puta ■



Richard Bergström, Krzysztof Maruszewski and Pekka Puska  
Francesca Colombo, Tim Nguyen and Stefan Schreck

## FORUM 5

Organised by DG Health and Food Safety  
(DG SANTE), European Commission





# Healthy ageing of workers

Health, safety and well-being throughout the working life cycle

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## WE ALL GET OLDER. THIS IS A VERY POSITIVE FACT!

However the new EU Strategic Framework for Safety and Health at Work 2014 – 2020 has identified demographic changes as a major challenge for the whole working environment and all stakeholders involved. The EU and all Member States have to react. Therefore, this workshop focused on the question: “How to improve the work and effort of all players in the labour market?”

Zinta Podniece, Policy Analyst at the Health, Safety and Hygiene at Work Unit of DG Employment, Social Affairs and Inclusion at the European Commission moderated the session and presented an interesting fact. While the total working age population will decrease in the future, the proportion of older workers will increase, comprising almost a quarter of the total working-age group by 2030. However, this potential will be lost if workers continue to leave the labour market before reaching the official retirement age.

## SAFETY AND HEALTH AT WORK - KEY FINDINGS

An EU pilot project called “Safer and Healthier work at any age” focused on examining policies, programmes and practices at the EU, national, intermediary and company level to identify success factors and obstacles. Katalin Sas, Project Manager, European

Agency for Safety and Health at Work (EU-OSHA) presented the following key findings. In general there are great differences between EU Member States in terms of demographics, economic and societal conditions, levels of awareness, and prevalence of age discrimination, priority approaches and policy action. Work-related health problems are the most prevalent reason for early retirement. Moreover, there are differences in the life expectancies of people with high and low education. In relation to these different situations in EU Member States, approaches also have to be adjusted. Best practice policies recognise the role of working conditions and try to support older workers by improving education at the workplace and giving financial support to employers.

## APPROACHES FOR ACTION

The fact that we have to work longer was highlighted as a major challenge for policies but also for ourselves. Christa Schweng, Senior Advisor, Austrian Economic Chambers, pointed out that there is a need to look at individual resources on the one side and on working environments on the other. Workplace health promotion is a volunteer activity for employers. There is no legislation on it and a lack of public support to adapt workplaces. She emphasised that it is necessary to focus on an integrated approach to guarantee workability through working life. This will be a benefit because reintegration of people would be much costlier than prevention.



Isaiah Durosaiye,  
Christa Schweng,  
Katalin Sas,  
and Gerhard Steffes

Heinrich Geissler, Managing Director, Consulting & Research - Geissler, conducted an instrument (WAI - Work Ability Index) to assess workability and to advise workability coaching during the life course based on the House of Workability. Each employee has to fill out the assessment regularly and if it shows a need for action, workability coaching will be conducted on a four-field approach considering Health, Management, Competence and Working Conditions. Regular assessment will be needed, because not all older workers maintain the same health status. The company "Böhler" in Austria started with this successful method nearly 20 years ago. Today they are seen as a best practice example.

Gerhard Steffes, Programme Management and Diseases Unit, DG SANTE, highlighted that there is a lot of knowledge and best practice available. Now would be the time to promote the exchange of expertise. Therefore it was part of the EU communication strategy to identify the 500 biggest health apps, which are depicted in a book available now.

Terje Peetso, Policy Officer, Health and Well-being Unit, DG CONNECT, also steered attention to the development of new and innovative technologies, stating they should be part of our normal life. From her perspective, digital health can help a lot - it can support employees, employers and health care systems.

At policy level the following key actions can be identified to ensure a sustainable working life as a precondition for a longer working life, higher employment rates and ultimately, better health for all:

- Cross-ministry cooperation and integration of policy frameworks including all relevant policy areas;
- Coordinated policy actions combined with a social dialogue.

## OUTLOOK

In order to spread information and knowledge to all EU Member States, the European Commission's DG Employment will advise Member States about the new EU Strategic Framework. They also will work together with the main stakeholders concerned and plan to bring out a campaign in 2016 and 2017 for raising attention to the topic of an older workforce. In addition, they will provide tools that can be used by Member States. All of the materials will be translated into national languages – for example the website and an e-guide where the purpose is to provide practical guidance for companies. In addition, a number of events and awareness raising activities will be organised over the next few years.

Despite these plans, there still will be some open questions which should be tackled in the future. Isaiah Durosaiye, Research Assistant, University of Central Lancashire, addressed them:

- In which health conditions are employees able to work longer?*
- How to embed legislation in every cultural practice?*
- How to retain older employees who are still in good health?*
- How to use technology to support older people?*

Finally, a holistic approach and the high efforts of all stakeholders will be needed to strengthen the benefit of older workers in the labour market, because, as Heinrich Geissler said: "Sickness-absence is a cost factor - promotion of workability is an investment!"

■ Written by Kathrin Hofer ■

## WORKSHOP 1

Organised by DG Employment, Social Affairs and Inclusion (DG EMPL), European Commission

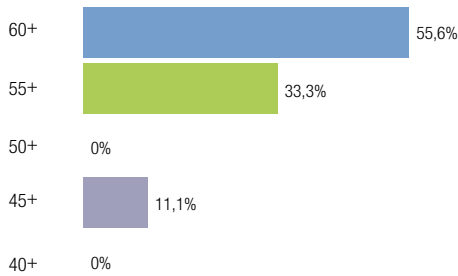


# VOTING RESULTS

Participants of the workshop session were asked to answer several questions relating to the subject of the debate.

To access full voting results please visit our EHFG 2015 archive.

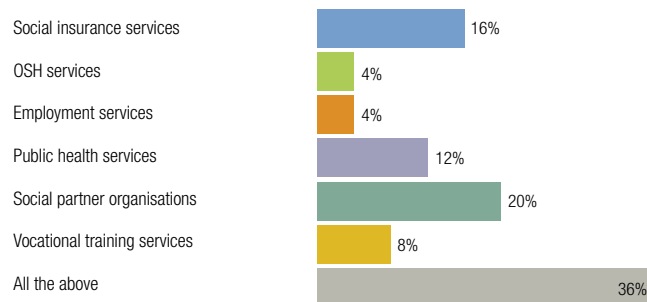
Q1. In your opinion, an older worker is...



Q4. In your opinion, what are the most important measures to keep ageing workers healthy and longer at work? [can choose max 3 answers]



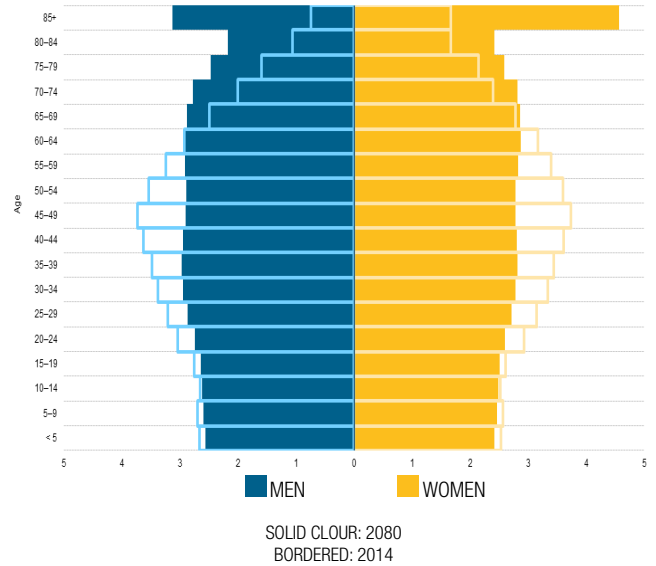
Q5. Ageing workforce is a cross-cutting issue involving many different players. In your opinion, which ones play the most significant role in ensuring healthy and sustainable working lives? [can choose max 3 answers]



# POPULATION STRUCTURE AND AGEING

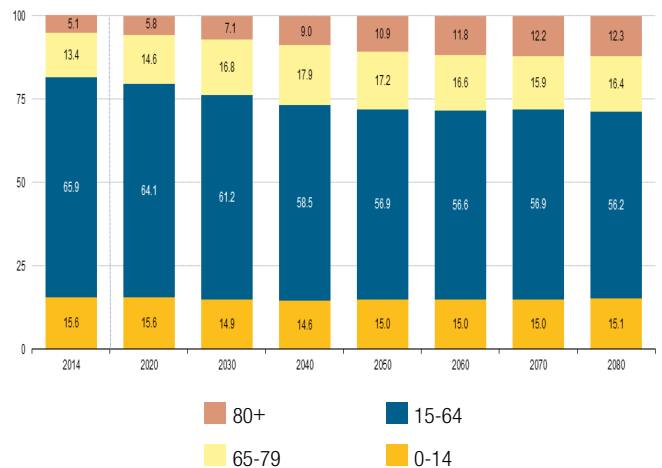
The charts below show the future population ageing trends in the EU, based on the Eurostat information from June 2015.

Population pyramids, EU-28, 2014 and 2080 (1)  
(% of the total population)



(1) 2080: projections (EUROPOP2013). Eurostat (demo\_pjangroup) and (proj\_13npms)

Population structure by major age groups, EU-28, 2014–80 (1)  
(% of total population)



(1) 2020-2080: projections (EUROPOP2013). Eurostat (demo\_gind) and (proj\_13npms)

Source: Eurostat, Population structure and ageing (Data extracted in June 2015)  
URL: [http://ec.europa.eu/eurostat/statistics-explained/index.php/Population\\_structure\\_and\\_ageing](http://ec.europa.eu/eurostat/statistics-explained/index.php/Population_structure_and_ageing) (01.03.2016)





# Financing of NCDs

Non-communicable diseases: financing costs by public and private actors

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The session started with a welcome by Helmut Brand, President of the European Health Forum Gastein, who then handed over to Oleg Chestnov, Assistant Director General at the World Health Organization. Chestnov stressed the main aim of the workshop - sharing thoughts, opinions and visions between all stakeholders in order to find a common approach to the sensitive matter of financing NCDs with the involvement of the private sector. Referring to paragraph 44 of the new sustainable development agenda, he reminded the audience that if we are to achieve our global health target goals a dialogue with the private sector is necessary. But a key question is how to meet half-way?

Before the floor was given to the audience and panellists, Bente Mikkelsen, Head a.i. of the Secretariat for the WHO Global Coordination Mechanism on the Prevention and Control of NCDs gave a short presentation on the coordination mechanism and addressed the question of how to work together with the private sector from the WHO perspective.

The goal of the Coordination Mechanism is to bring key stakeholders together, especially non-state actors and to give an equal stake in the process to all. To facilitate and enhance coordination of activities, multi-stakeholder engagement and action across sectors at the local, national, regional and global levels is needed, in order to contribute to the implementation of the WHO Global NCD Action Plan 2013-2020.

## GOAL 3

Ensure healthy lives and promote well-being for all at all ages



### GOAL 3 TARGETS

(...)

3.4

By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being

(...)

3.b

Support the research and development of vaccines and medicines for the communicable and non-communicable diseases that primarily affect developing countries, provide access to affordable essential medicines and vaccines, in accordance with the Doha Declaration on the TRIPS Agreement and Public Health, which affirms the right of developing countries to use to the full the provisions in the Agreement on Trade-Related Aspects of Intellectual Property Rights regarding flexibilities to protect public health, and, in particular, provide access to medicines for all



Source: UN Sustainable Development Knowledge Platform  
URL: <https://sustainabledevelopment.un.org/sdg3>

Since the adoption of the Sustainable Development Goals in September 2015, tackling NCDs is officially an important part of the agenda. An estimated 175 trillion dollars are required to finance and implement the SDGs. In her presentation Mikkelsen mentioned the ground-breaking agreement, the Addis Ababa Action Agenda, which provides a foundation for implementing the Global Sustainable Development Agenda - financing is considered the linchpin for success.

Mikkelsen then discussed draft recommendations and key findings on how to realise governments' commitment to provide financing for NCDs and to engage with the private sector for the prevention and control of NCDs.

The Addis Ababa Action Agenda recommends promoting financing and engagement from the private sector in addressing NCDs. Reporting on the findings, Mikkelsen underlined the urgency to measure the contribution from the private sector, the need to develop a tool for governments to engage with the private sector and, importantly, to differentiate between parts that do and do not conflict with health goals. However, we are still lacking a framework for such cooperation.

## ACCESS TO PHARMACEUTICALS AND THE NEED FOR WORKING WITH THE PRIVATE SECTOR

Minister of Health of Albania, Ilir Beqaj, talked about the situation in his home country - how the government of two years set a milestone through dialogue and cooperation with the private sector, focusing on access to essential medicines. Beqaj explained that most medicines in Albania were more expensive than in their country of manufacture - even generics were more expensive than patents. Albania just started introducing reference prices, adopting the EU regulations. The Albanian Ministry of Health tried a new approach in working with the private sector, not to deal with companies individually, but taking it to a level above and liaising and negotiating with their associations. Beqaj considered it important to keep an equal distance from each player in the process.

"If we don't shift from sickness to health, then, I believe, we are lost. We will not have the leadership and would rely only on what the industry would provide. We should agree on a direction to go and invite the private sector to try to re-shape themselves in order to find a common approach."



## THE ADDIS ABABA ACTION AGENDA

Financing is considered the linchpin for the success of the new sustainable development agenda (...).

The outcome document also underscores the importance of aligning private investment with sustainable development, along with public policies and regulatory frameworks to set the right incentives.

Source: United Nations, Third International Conference, Financing For Development  
URL: <http://www.un.org/esa/ffd/ffd3/press-release/countries-reach-historic-agreement.html>

He also mentioned the collaboration between the SEEHN governments, seeking multinational procurement, as an opportunity to achieve a synergistic effect when collaborating with the private sector.

Following these two talks, invited representatives from the private sector shared their views and experiences: Morten Frank Pedersen, Executive Government Affairs Advisor, Novo Nordisk; Peter Dyst, Health Economics Officer, European Generic and Biosimilar Medicines Association (EGA); and Andrey Potapov, General Director, Head of the CIS Area, Takeda Pharmaceuticals LLC, Russian Federation.

Pedersen tried to shed some light on the grounds for a successful public-private-partnership:

- Transparency
  - between the collaborators and to the outside
  - about roles
  - about perspectives
- Clear goals, roles and responsibilities
- Monitoring of the ongoing process

He recalled a collaboration between the public sector, civil society and his company, launched in 2012, stating that the most difficult part was to establish roles and responsibilities between the different parties - which finally led to the signing of a memorandum of understanding by all parties involved.

In Dyst's opinion, governments should embrace generic medicines, increasing volume with lower costs, thereby making room for funding of innovative and high-priced medicines. He also stated

that an educational process within society and governments is needed, as in some European countries there is still much distrust towards generics.

Before the floor was given to the audience, Ketevan Goginashvili, Chief Specialist, Ministry of Health and Social Affairs, Georgia and Abdunamon Sidikov, International Cooperation Department, Ministry of Health, Uzbekistan made short interventions outlining the situation in their countries. Both Georgia and Uzbekistan are developing standards for public-private sector cooperation and are at the very beginning of the process. Georgia just began its experience with public-private-partnerships i.e. a PPP to tackle Hepatitis C. Uzbekistan's government is setting investments in healthcare and prevention high on the agenda. By opening up market access to the private sector, Uzbekistan is hoping to broaden competition and in the longer-term to lower prices. However, in both presented cases a firm framework for public-private cooperation is still lacking.

## DIALOGUE - WHERE TO START?

A question posed to the audience was: Where to start the dialogue?

A GlaxoSmithKline representative addressed the issue of mistrust towards pharmaceutical companies that has already been discussed in the session. He stated he would welcome more openness from the non-political part of society, as well as efforts to also see positive aspects of the industry. Otherwise, in his opinion it will be difficult to start a dialogue. This was challenged by an opinion from a corruption network representative, who could not share that optimistic wish. This representative stated that the Corruption Network does not trust the industry, whether it is tobacco, pharma, alcohol or food, because their interest simply does not lie where the patients' interest lies. He suggests a bottom line, where it should be up to governments to set the rules of the game.

There was also a cool yet hopeful voice from the audience from a representative of the European Cancer Leagues. ECL sees itself somewhere between the two attitudes towards industry previously discussed. The problem of mistrust and distrust is created by the lack of dialogue. Where civil society would welcome strong involvement from the private sector is in the area of support and collaboration towards health prevention.

A representative of the Russian Oncology Association suggested that when addressing the issue of private sector engagement, governments should also involve actors making the financial decisions in the discussions - the insurance sector for instance, which possibly could be a good link between public and private sectors.

As one member of the audience put it jokingly: "Industry is like a teenager - it needs to be given boundaries". To recapitulate, through results from the lively debate and discussions one can state that there are a number of conditions needed for a PPP to succeed in the sphere of financing NCDs:

- The solution needs to come from countries/governments - but not without the help of civil society and the involvement of the private sector
- Try new approaches in working with the private sector, as i.e. MoH of Albania did - work with associations, not individual companies and keep an equal distance to each party involved
- Start collaborating (stop fighting first)
- The process must be transparent inside and outside
- Goals set should be the same for each party involved

Such conditions were on the face of it simple and obvious for all involved in the debate, yet it was recognised that in reality they are hard to achieve.

■ Written by Maria Dziubinska ■

## WORKSHOP 2

Organised by World Health Organization





# Mental health

Innovative solutions for preventing and treating mental illness

Mental disorders place a heavy burden on Europe, both on the individual and at societal level. Many new ideas and models of prevention and care are being developed and tested, including various e-tools. The session on mental health, moderated by Ann Uustalu, DG Research and Innovation, European Commission, aimed to explore innovative solutions for preventing and treating mental illness. The session specifically focused on how societies can best take advantage of the innovation and technological progress available to us in preventing and treating mental disorders.

Helen Christensen, from the Black Dog Institute, University of New South Wales (Australia), illustrated innovative evidence-based e-tools to inform and support people suffering from mental disorders in Australia. Australia has been a leading country in developing Information and Communications Technology (ICT)-based approaches for several areas of medical interventions, including psychiatry.

It is possible to identify four models of “first generation” services providing web-based support for mental disorders:

- Automated systems that offer prevention, self help and self-care
- Consumer assisted care
- Virtual clinics
- General practice models



A major problem of these systems is a lack of evidence-based reliability (i.e. the majority of them were not supported by reliable randomised controlled trials data) as well as a lack of integration between automated web activities and daily clinical practice.

Subsequently, Australian researchers have developed a model focused on reliability and integration. This “second generation” system integrates specialist clinics with e-mental health services and general practice referrals. The model is also currently



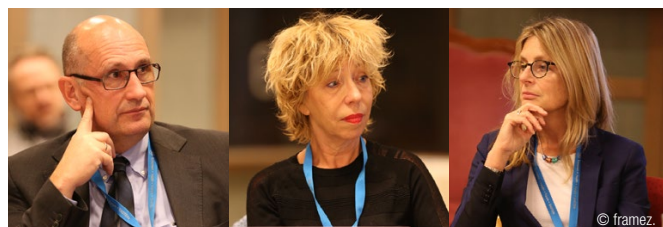
developing a range of community-accessed services that will link into the current face-to-face activities via a web-platform. The virtual clinic for university students led by the Australian National University and the virtual psychiatric clinics for young people led by the Brain and Mind Research Institute are among the most prominent examples of this integrative approach.

However, according to Christensen, we need a “third generation” of e-mental health solutions, aimed at:

- providing consolidation of specific domains (i.e. promotion, prevention, intervention, treatment and recovery),
- introducing screening and continuity of care solutions,
- integrating with face-to-face psychiatric practice and
- promoting availability of integrated ICT-based health services.

Bert Aben is a board member of GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks-Europe), a patient-driven pan-European organisation which represents the interests of people affected by mental illness and advocates for their rights. Aben, who was diagnosed with a psychotic disorder at the age of 31, highlighted the importance of good communication with healthcare providers for patients with mental disorders. Physicians should put more effort in having active and effective communication with patients. Stronger contact between patients and health professionals could lead to better clinical and social outcomes in psychiatry.

Heleen Riper, Professor at the VU University of Amsterdam, discussed the idea of a comprehensive approach concomitantly driven by patients, science and values. She gave an overview of the experience with e-mental health in The Netherlands, which have been establishing ICT-based mental health services for 20 years and are a leading country in the field. Services of e-mental health in The Netherlands are promoted by the Ministry of Health and are included in insurance systems; the government expects that in 2020 80% of people with chronic diseases will have access to these services.



Claus Duedal Pedersen, Heleen Riper and Helen Christensen

Finally Claus Duedal Pedersen, Chief Innovation Officer of the Odense University Hospital in Denmark, presented the MasterMind project - Management of mental health disorders Through advanced technology and services - telehealth for the MIND. This project is driven by a consortium of European countries including Denmark, Scotland, Wales, The Netherlands, Germany, Estonia, Spain, Italy, Turkey, Norway and Greenland. The MasterMind programme involves services of computerised cognitive behavioural therapy and video conference networks, and it targets adult individuals suffering from moderate or severe depression.

The ambitious objectives of this project are:

- Up-scaling the ICT-based mental healthcare services in regions/countries where these have already successfully been implemented
- Triggering the uptake of ICT-based mental healthcare services in regions new to this kind of approach
- Demonstrating the favourable cost-effectiveness of the services, confirming that the clinical outcomes obtained through these services are not inferior to those of traditional care
- Reducing the waiting list and improving equality of access to mental healthcare

■ Written by Francesco Saverio Bersani ■

## WORKSHOP 3

Organised by DG Research and Innovation  
(DG RTD), European Commission



# From citizen to citizen

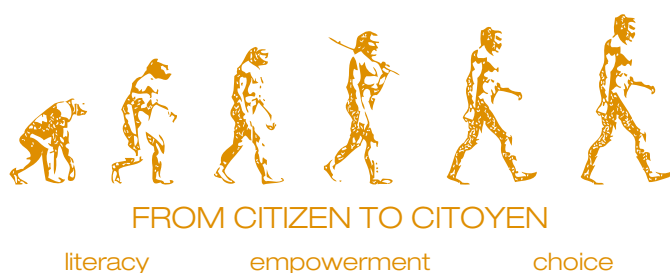
Ground-breaking innovations in the field of technology and e-health contribute to the empowerment of citizens, and thereby strengthen healthcare systems. In this workshop, leading experts from various fields of work shared their experience with digital innovations and strategies to empower patients, and discussed future approaches to improve European healthcare, based on best practice projects. They attempted to answer how we could secure accessible and affordable healthcare when facing demographic changes and consequences of the financial crises.

When introducing the subject, moderator Hédinn Svarfdal Björnsson, Directorate of Health, Iceland, emphasised the importance of the transformation from citizen to citizen. The latter participates actively in a political life within a community, being able to enjoy positive freedom. The citizens, here synonymous with empowered patients, are in control of their health data, and are able to shape, and reform the health systems due to their knowledge and capacity.

Terje Peetso, Policy Officer, Health and Well-being Unit, DG CONNECT, European Commission, started the discussion by pointing out the relationship between responsibility and empowerment. In her opinion, it is important to give power to people who are already responsible. Since digital tools can facilitate the fulfilment of various responsibilities, patients can exercise their power by using technology. Therefore, a vital objective of the digital agenda of Europe is to ensure everybody's access to the knowledge available online, as well as to the relevant digital devices. Horizon 2020 focuses on the end users' involvement. By listening to the patients' needs and problems, the end-user can be engaged from the beginning, and tools and programmes can be designed consequently as simple, user friendly and effective.

However, according to Angela Brand, European Alliance for Personalised Medicine (EAPM), it might be very difficult to implement innovations, since you interfere with the preferred status quo. Nevertheless, things begin to change and innovations in the technological field can lead to direct access to information for the citizens.

This democratisation of information represents a challenge for health professionals. What information is useful for the person, at what time and for what purpose? It appears that citizens would like to have access to all information. In order to apply the right information, health literacy is of vital importance. With its four



dimensions (ability to access, understand, appraise and apply the information), it might become a cornerstone of the politically responsible citizen, the citizen. Additionally, Brand emphasised that health literacy is not only a bottom-up movement to empower citizens, but also a top-down process, where governments should offer citizens more choices. Since patients have become holistic data creators (economic, social, biological data), healthcare professionals need to translate this dynamic into healthcare systems. Working in interdisciplinary teams enables health professionals to interact with IT experts and exchange knowledge to foster innovation and the development of appropriate tools. In response to the question raised by the audience of whether there is any ambition to involve end-users, not just in the first phases, but also in the evaluation of the project progress, the panel highlighted the significance of such a long-term commitment - particularly in Horizon 2020.

Christian Franken, Apollon University of Applied Sciences, Germany, initiated by comparing the transformation process of citizen to citizen to the empowerment of citizens, since both processes are very similar. He focused on both the start and the end phase of such a process. Firstly, health professionals have to analyse the fears and demands of patients. "Without this, any programme won't work, or at least won't work as efficiently as it should!" Surveys have shown that for example in the Netherlands, 96% of the Dutch population use apps very often, whereas only 6% use health apps. According to Franken, this is due to patients' lack of interest and understanding of their chronic illness. Listening very carefully to patients' needs and concerns, as well as making them interested in their own disease, is vital for the successful development and implementation of health apps. Equally important as the involvement in the opening phase is the evaluation phase at the end of the process, based on clear, solid indicators preferably across the EU.

Max Müller, DocMorris, The Netherlands, stressed the significance of price for patients who want to have access to a medicine of good value. DocMorris provide their patients with a financial incentive by offering reduced co-payments and other monetary benefits. Due to this procedure, the chronically ill can interact on an equal basis with their physicians. In line with the other



Christian Franken, Angela Brand, Kristine Sørensen and Max Müller

panellists, Müller supported the aspect of active listening to patients and involving them in the process. For citizens who are healthy, or at least who think they are healthy, health literacy seems less important, since they have less interest than those personally affected. Nevertheless, it is essential to use simple, easy and understandable tools. Empowerment, therefore, can work if policy-makers and health professionals take it seriously and speak in a language the patients understand.

Tobias Gantner, HealthCare Futurists, emphasised that innovation comes from democratisation, and since healthcare is a rather non-democratic market, patients are seeking reformation. In his remarks, he compared healthcare with a sort of modern public religion, with physicians as high priests. He added that a citizen is a democratised person who is looking at his/her own healthcare data and sharing this data with others. Furthermore, he outlined a transformation from prescribed medicine based on establishments to participated and preventive medicine based on evidence. According to him, healthcare is about the distribution of knowledge, which leads to very well informed and educated patients. "These patients - this much is certain - will go their way and they will not wait for Horizon 2020, nor political decisions", concluded Gantner. Access to information is easier than ever, but finding the right information is the crucial aspect.

To illustrate her elucidations on health literacy, Kristine Sørensen, Health Literacy Expert, Assistant Professor, Department of International Health, Maastricht University, gave a glimpse of the story *The Hitchhikers Guide to the Galaxy*. As a result, she showed that patients might be disinterested or not participating in apps because there is a lack of knowledge, expertise, information and willingness to participate. Thus, with regard to Sørensen, we have to learn from the story of the Hitchhiker that we cannot take it for granted that citizens are well-informed about what innovations are currently present on the market. Finally, she underlined the importance of investment and support for health literacy to ensure a high quality of life.

All the panellists agreed that in order to sustainably empower the European patient, the whole EU needs a map of health literacy. In addition, early engagement and active participation from the end-user throughout the whole process is indispensable. Finally, innovative technologies will have a growing impact in European health systems and we should make the most of it.

■ Written by Anna-Sophia Bilgeri ■

## WORKSHOP 6

Organised by Maastricht University in cooperation  
with DocMorris





# Workforce skill-mix

## Improving the skill-mix for chronic care

People frequently say it's the people who make a health service. Representing by far the greatest cost base to the average healthcare provider, it's true that the workforce makes a huge contribution to health system performance. Getting the human resource input right - so that the right people are delivering the right care at the right time - is a strategic priority for health system strengthening across European Member States.

Workforce skills mix refers to the combinations of skills, activities, posts and grades needed to deliver optimal care to a patient, both in terms of quality and efficiency. The aim of the workshop, chaired by Tania Dussey-Cavassini, Vice-Director General, Federal Office of Public Health, Switzerland, was therefore to discuss how innovations in skill-mix can contribute to improving the delivery of high quality efficient health and social care. The discussion was in particular focused on how optimising skill-mix can:

- Enable and support service users and their carers
- Coordinate services and overcome fragmentation
- Drive efficiencies
- Increase capacity and capability of primary care and secondary care

The workshop saw presentations and discussion from the panel: Yann Bourgueil, Director at the Institute of Research and Information for Health Economics, France; Claudia Maier, University of Pennsylvania, Centre for Health Outcomes and Policy Research,

USA and a Young Forum Gastein Scholar; Martin McKee, Professor of European Public Health and the London School of Hygiene and Tropical Medicine and Monika Diebold, Director of the Swiss Health Observatory.

### PERSON CENTRED CARE

Integrated care is certainly a current buzz phrase amongst policy-makers across Europe, however all too often we still encounter institution oriented concepts of care delivery. In this workshop, it was encouraging to hear definitions of skill-mix concerned with designing care around the patient. The panel opened discussions by stating the pressing need to coordinate a workforce so it can deliver integrated care from the best team to the patient.

They agreed that skill-mix is how to organise people into this team. This clearly set the precedent for the afternoon's discussions; that the patient should be the organising principle of service delivery and that the workforce should be configured with this premise at the fore.





The workshop discussion revealed a number of challenges for workforce management:

- Workforce shortages
- Barriers to behavioural change
- Fragmented models of care
- Regulatory and payment system barriers

A number of important solutions were raised as potential ways to address these challenges.

## BREAKING THE MOULD

Innovation - for instance through task shifting and the creation of new job roles - was discussed as a way to address some of the challenges facing workforce policy-makers and managers today. We heard examples from across the world: how the USA have a long history of using Nurse Practitioners, highly skilled and highly qualified nurses often found working in primary care. They fill the skills gaps resulting from a shortage of primary care physicians. It was highlighted that Nurse Practitioners were also more likely to be found in rural areas, further balancing the medical doctor skills shortages. In Germany, a shortage of primary care physicians drove the introduction of Medical Assistants, a post that requires three years of training, to be employed to assist GPs in case management. In Finland, training nursing students in pharmacology was found to be a way to efficiently meet the need for this skill on the wards. The UK has emphasised the use of nurse consultants, specialists in a particular medical area who undertake chronic disease management and who are skilled and remunerated at equivalent level to doctors. Innovations such as these can address needs-based shortages and address skill-mix imbalances.

## PILOTS TO EVIDENCE AND SCALE UP SUCCESS

Yann Bourgueil presented a case study from France, where a shortage of doctors led to a national debate on possible solutions. Building on evidence from the US, Canada and the UK, a skill-mix pilot for the management of type 2 diabetes was launched where tasks were transferred from doctors to nurses whilst maintaining and indeed improving quality of care and health outcomes. Nurses were given responsibility for additional tasks, such as

face to face consultations with patients. The pilot, now running for ten years, shows promising results with doctor contacts and overall activity reduced among patients as a result of focused preventative case management. The pilot is a good example of navigating regulatory barriers, having successfully implemented a payment approach that incentivised the desired behaviours among practitioners. Evidence from pilots is essential to identify and then scale up successful models of care. However, this is not without its difficulties. The phenomenon of un-scalable pilots is well, if only anecdotally, documented. The panellists emphasised that pilots often flourish under specific systemic conditions which may not be relevant or replicable elsewhere (strong leadership, ability to experiment, legislative and regulatory landscape). Regardless, pilots remain a fundamental tool for policy-makers; rather than continually letting a thousand flowers bloom, strong empirical evidence from pilots enables the design and delivery of specific evidence-based change.

## MULTIDISCIPLINARY WORKING

Skill-mix innovation is inextricably linked with multi-disciplinary working. For instance, skills gaps can be covered through cross-disciplinary working, rather than waiting for new recruits to move through training posts. Multi-disciplinary working has proved to be effective in a wide variety of clinical areas. The approach is able to add value through sharing the workload more cost effectively amongst practitioners.

## COMMUNICATION AND SHARED DECISION-MAKING

With multidisciplinary working comes a need for clear and effective communication. Patients need people caring for them who know how to listen and who know how to make decisions across disciplines to plan their care. However, an increasing focus on communication and shared decision-making is not without its challenges. Martin McKee argued that an increase in case management approaches delivered by multidisciplinary teams (MDTs) has led to a proliferation of MDT meetings, threatening the time staff can dedicate to patients themselves. He warned policymakers not to lose sight of the fact that patients and patient-focused care delivery should be at the heart of all workforce reform.

## BE CLEAR ON YOUR GOALS

The panellists were clear: skill-mix innovations can lead to cost effectiveness and increased efficiency but do not necessarily deliver immediate savings. It was agreed that you cannot save money quickly by re-coordinating skills. It often takes a long time for a small population of professionals to change. Instead, skill-mix innovations should be seen a part of a long process; a way of transforming your production and investing in quality over time.

## CONCLUSIONS

- Consensus: there was consensus on the panel on what skill-mix initiatives are trying to achieve, the challenges they face, and how they can be overcome.
- Diversity: the wide variations in how European countries configure their workforce offers opportunity for comparing skill-mix reforms; the evidence is there, it seems now we need to focus on ways to effectively share learning.
- Looking ahead: it was clear that skill-mix innovations need to be borne out of long-term strategic perspectives. There are rarely “quick wins” or “big bangs”; this is about long-term quality improvement through effective human resource coordination.

■ Written by Elinor McDaniel ■



Francois Schellevis, Yann Bourgueil  
Monika Dieblod

## LUNCH WORKSHOP 3

Organised by Swiss Federal Office of Public Health in collaboration with the European Observatory on Health Systems and Policies





# Empowerment in practice

## Self-management of healthcare

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This workshop was centred around the European Patients' Forum-led campaign on patient empowerment, called "Patients Prescribe". Research has shown that patient-centred care models are cost effective and lead to better health outcomes and patient satisfaction. Patients and healthcare professionals (HCPs) need to become equal partners when discussing and making choices that concern patients health. The session was moderated by Tamsin Rose, Non-resident Fellow, Friends of Europe.

### CONCEPT OF EMPOWERMENT

Martha Ballester, Project Coordinator, Avedis Donabedian Research Institute, University of Barcelona, presented the main outcomes of a project on patient empowerment by the EMPATHiE consortium. Setting the scene for the workshop, she defined patient empowerment:

"Empowered patients have control over the condition in their daily life. Secondly, they take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to achieve optimal well-being". Patient empowerment should also be interpreted as a process that goes beyond the individual level. It provides patients with the tools to collectively stand up and influence rules and regulations affecting them.

Studies on the efficacy of patient empowerment in a wide spectrum of disease areas have multiplied over the years. A group that is still overlooked in the studies is the one of patients with multiple diagnoses, "complex patients", covered so far in only one study. Furthermore, there is a gap in the literature on shared decision-making between healthcare practitioners and patients, with the exception of cancer research. The outcomes in the latter are very promising and could be translated into other areas. Finally yet importantly, the evidence for self-management with the help of technology is inconclusive.

The EMPATHiE consortium found overwhelming evidence that empowerment strategies in general worked.

The project also aimed to identify the perceived barriers to patient empowerment in Europe. With the help of focus groups consisting of patients, HCPs, health managers and experts from 18 countries, five top priorities were identified. However, the ranking of these five priorities varied among the stakeholders. Patients for example, considered more time with HCPs of key importance, while for HCPs the need for patients to feel responsible for their health was the top priority. Hence, more work needs to be done in close coordination with the different stakeholders to further improve patient empowerment and create better mutual understanding between HCPs and patients.

In conclusion, Ballester highlighted the lack of patient representatives at events by the European Union institutions and

academia, emphasised the difficulty of spreading best practices on patient empowerment across Europe and stressed the need for more research to fill the identified gaps. She stated: “Healthcare has to catch up with the rest of society when it comes to empowerment”.

## EMPOWERMENT IN PRACTICE

The subsequent three presentations focused on the implementation of theoretical concepts.

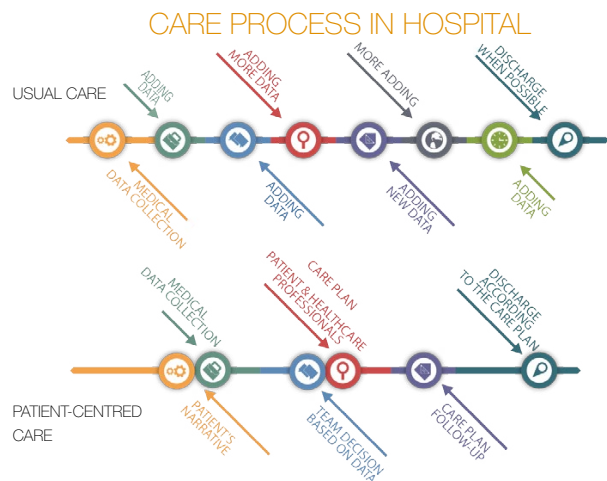
The first one was conducted by Tamsin Rose on behalf of Theo Raynor, Professor of Pharmacy Practice, University of Leeds, UK, who was unfortunately unable to deliver his presentation in person. Raynor’s main message was that any information addressed to patients needs to be relevant, accessible and understandable. Information through education is the most important E in the 5 E’s of empowerment: Education, Expertise, Equality, Experience and Engagement. Health literacy deserves a holistic approach and needs to focus on all layers of society instead of targeting one particular group. As a rule, only information that is “fit for purpose” should be communicated. All other information should be eliminated. One important measure to realise this goal is user involvement. Information materials should be tested on groups of patients before circulation. If patients receive the chance to make choices, they will make them. An informed patient is not automatically an obedient patient and may ignore the advice of the HCPs. An empowered decision remains a positive outcome.

Professor Inger Ekman, Director, Centre for Person-Centred Care, University of Gothenburg, Sweden was the next speaker. She provided a successful story of patient empowerment in practice. The key to success was to better listen to the patients, a factor often neglected by the HCP due to a lack of time. HCPs and patients together developed a treatment plan, where not all the goals related to curing the disease or extending life years. Patients often attributed more value to health gains such as more sleep, feeling less stressed or being able to be more active. The treatment plans in this case were interpreted as a contractual agreement between the physician, nurse and patient and covered a combination of HCPs’ and patient’s goals. The plan could also be shared with General Practitioners or other HCPs at a later stage. The positive effects of using this type of treatment plan

Figure 1: Example of Person-centred care plan

Person – centred Care plan		FEMALE patient, 61 years old			
Resources / Barriers – Motivation – Personal goal					
Goal setting (return to desired activity): To lower stress level, to calm down and do one thing at a time. To pursue more of own personal interests.					
What and how should I do this? When? To learn to say 'no'. To dare ask for help. To not always try and do things on one's own.					
My own resources and capabilities (How can I use these to achieve my goal?) Artistic and creative. Paints a lot and feels great doing that. Purposeful and decisive. Knows about her risk factors. Has good friends for support.					
My need for support: Need to be in touch with a professional person (psychologist) to help with managing stress and finding tools to deal with internal stress					
Team decision (A)					
To be completed by physician, nurse and patient					
PCC plan prepared prepared and agreed as per patient's requests and wishes	<input checked="" type="checkbox"/>	Yes No			
Discharge planning, anticipated discharge date: 05.12.2013	<input checked="" type="checkbox"/>	Yes No			
Next of kin informed about PCC plan in accordance with patient's requests and wishes:	<input checked="" type="checkbox"/>	Yes No			
Are there any anticipated complications in the PCC planning?	<input checked="" type="checkbox"/>	Yes No			
Anticipated complications: If no coronary angiography: 4/12					
Signature patient: E. Ekman	Signature physician: A. Eriksson	Signature nurse: H. Carlsson			
Date: 02.12.2013	Date: 02.12.2013	Date: 02.12.2013			
Wellbeing (B)					
Symptoms assessed by patient every 48 hours					
Date	Day 1	Day 3	Day 5	Day 7	Discharge day
Dyspnoea <sup>4</sup> (1-5)	3	1			1
Fatigue <sup>4</sup> (1-5)	4	2			3
Health <sup>5</sup> (0-10)	5-6	4-5			4
Pain <sup>5</sup> (0-10)	3	3			3
Sleeping well (yes/no)	No	No			No
Depression <sup>5</sup> (0-10)	4	2			2-3
Anxiety <sup>5</sup> (0-10)	4	4			6
Other symptoms	Numbness left arm				
4: Likert scale, 5: Visual Analogue Scale					
Evaluation (C)					
by patient					
I was involved in my care planning	<input checked="" type="checkbox"/>	Yes No			
I was involved in discharge planning in a satisfactory way	<input checked="" type="checkbox"/>	Yes No			
Continued PCC plan (C)					
Patient keeps PCC care plan and brings it to appointment					
2 days after discharge the patient will be contacted by primary care centre					
Contact at primary care centre: L. Sjöstrand Telephone number: 022 345 678					

A= Patient narrative; B= Symptom monitoring; C= Evaluation/discharge planning



Source: Inger Eckman, Patient-health professional relationship. The benefit of effective participation and self-management by patients (Power Point Presentation, October 2015)

were reduced uncertainty in illness, improved self-efficacy, reduced symptom burden, improved quality of life and reduced hospitalisation (30-50%). All in all, the introduction of treatment plans for patients have the potential to reduce cost for care by 40%. The facts presented were well received in scientific journals and should now be communicated to politicians for whom these outcomes are of key interest for their work. Ekman concluded that a patient should be an eligible partner while deciding upon his or her own health, that a patient treatment approach is feasible in all patients, and that patient centred care is cost effective. HCPs might unfortunately not be ready (yet) for these changes.

Nicolaj Holm Faber, Chief Consultant, Danish Committee for Health and Education, Denmark, presented his views on patient empowerment. He fully endorsed the previous presentations by his colleagues and in particular shared their criticism of HCPs. In Denmark an experiment was conducted which showed that patients would go to the right place if signposts in hospitals contained “lay messages” instead of medical terms. HCPs are against this “unprofessional” marking as it may, according to them, be badly perceived by their colleagues in other countries. Following Eckman, he argued that HCPs do not listen to patients despite the fact that research proves listening to patients is time saving in the long-run.

Holm Faber continued by explaining that on average 2% of our time is spent with HCPs, while 98% of the time we deal with health issues ourselves. Hence, capacity building should aim to help patients through the 98% of their health related self-management instead of focusing on the remaining 2%. In Denmark, Holm Faber and his colleagues worked for 10 years on introducing self-management. The argument he and his colleagues used most of the time was related to the Expertise as one of the 5 E's in patient empowerment. There is so much Expertise hidden in that 98% of self-management which typically remains unused. After focusing for decades on training doctors and nurses, it is time that we now place our focus on the patients.

Camille Bulot, Young Forum Gastein Scholar and Membership Officer of the European Patients' Forum, replaced EPF President Anders Olauson for his speech on the 5Es campaign. The campaign supports the implementation of patient empowerment in the different healthcare systems and hence benefits the sustainability of the systems.

Bulot called upon delegates to support the campaign by signing the online pledge, taking a picture of the pledge and posting it on social media, writing a testimonial on the EPF blog and/or organizing their own event on patient empowerment. It is crucial that everybody understands what patient empowerment entails. The concluding message of the presentation, as well as the campaign, was that patients are active and assertive citizens who like to play a role in their own treatment. The audience was then shown the EPF campaign video where seven patients elaborated on the importance of patient empowerment.

Bulot stated: “I cannot give you the recipe to make healthcare systems more sustainable, but I can give you one ingredient: an empowered patient”.

The final speaker of the day was Eric Racine, VP and Head of Global Patient Advocacy at Sanofi, who presented the role of the pharmaceutical industry in patient empowerment. According to him, patient empowerment is already a reality thanks to the enormous amount of information available, particularly online. In addition to that, there are many patient groups fueling the development of pharmaceuticals.

Racine explained that “patient thinking” has started to become an important element in his company. An example is the influence patients exert nowadays at an early stage of the research process and all the way to the commercialisation of medicine. During the development phase, patients are actually involved 80% of the time. For research and pre-clinical phases, this number is only 15%. Racine admitted that to score better for the latter stages in the development process, cultural change is needed. He concluded by congratulating EPF on their empowerment campaign. EPF is according to him the global leader when it comes to patient issues.

## DISCUSSION

During the Q&A session, the audience was in general critical towards HCPs and called upon them to improve communications with patients. At the same time, HCPs were also defended by others, who suggested that there may be other factors such as legislation that limit the opportunities for HCPs to endorse patient empowerment. According to the panel, structural changes in combination with a cultural revolution are needed. Structural measures must focus on improving the education of HCPs and amending the rules and regulations they are bound by.

■ Written by Mischa van Eimeren ■

## LUNCH WORKSHOP 4

Organised by European Patients' Forum (EPF)

in cooperation with Sanofi









DIGITAL  
AND  
HEALTH

FORUM 1  
The power of data

FORUM 7  
Modern healthcare

WORKSHOP 10  
Beat the silence

part IV

# The power of data

The cutting edge of technological advances being used to understand health and health behaviours

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“SNIFF IT ALL, KNOW IT ALL, COLLECT IT ALL, PROCESS IT ALL, EXPLOIT IT ALL”

Martin McKee, Professor at the London School of Hygiene and Tropical Medicine (LSHTM), introduced the session and opened the discussions by personally thanking Edward Snowden. For those who are unaware, Snowden brought into the public domain the monumental amount of data that is collected - often without our awareness or consent - worldwide, every day. McKee highlighted very effectively, that in the “brave new world” of supermarket loyalty cards, consumers have little choice in the information they share with the world. Citizens need to be aware that “information that we think is being kept secret, could be seen anywhere”. At the same time, massive data collection opens up unprecedented opportunities for healthcare. For instance, crowd-sourced applications allow identifying outbreaks of disease in real-time, largely before governments or international institutions, such as the WHO, themselves are aware. McKee closed his introduction by suggesting that possibly, with sufficient safeguards, we can use this information not only for advertising junk food, cigarettes or luxury goods, but “for doing some good” and promoting health.

## SOCIAL MEDIA AND HEALTHCARE SURVEILLANCE

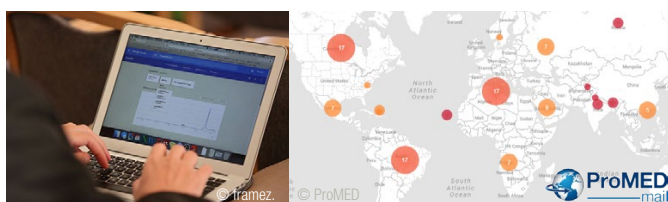
Following the introduction, Rachel Loopstra, a research fellow at the University of Oxford, gave us an insight into “Social Media as surveillance and as a public health intervention”.

### Tracking mental health

Rachel discussed how researchers analysed the impact of the Seoul Ferry disaster (South Korea, 2014) on mental health using social media data. Text mining algorithms were applied in social media to identify expressions of sadness and anxiety, as well as the occurrence of keywords linked with suicide risk and depression. The working group found that even many months after the tragic event, there were sentiments of pain, despair, tragedy and shock being expressed at higher than usual levels. Although this study exemplified how public health agencies can keep track of mental health states, it is still unclear what actions can be taken to prevent suicides. Nonetheless, Loopstra's case study powerfully demonstrates the opportunities of social media data: they represent unsolicited data that is available in real-time and at low costs.

### Analysing risky health behaviour

Moreover, Loopstra presented an interesting example of using Twitter data to analyse people's perceptions about alternative tobacco products such as e-cigarettes and hookah. The study found that shisha and hookah products tend to have positive



sentiments associated with them, while negative feelings are linked to cigarettes and tobacco. Public health agencies can utilise this knowledge for reducing health threats by informing people about the dangers of these allegedly harmless products. In view of the hyperbolic expectations of social media research for health, Loopstra finished her session by highlighting its limitations. Social media data suffers primarily from a selection bias, with young, well-educated people being over-represented. Furthermore, users' desire of creating a positive, self-projected image of themselves might hamper a fair representation of their true opinions, emotions and behaviour.

## SOCIAL MEDIA AND HEALTHCARE INTERVENTION

### The rise and fall of Google Trends

After having heard how social media can be used to improve health surveillance, Dr Aaron Reeves, Senior Research Fellow at the University of Oxford, addressed the audience with his presentation on creating healthcare interventions based on internet usage data and social media. First, he illustrated that tracking search terms over time with Google Trends can offer new insights into disease control. He then went on to show us how the mining of such data allows epidemiologists to predict the incidence of influenza in the population. He explained that, initially, Google Flu Trends reached an accuracy of up to 97% (compared to official data from the Centre for Disease Control [CDC]) in forecasting the number of cases presenting at a surgery with flu-like symptoms. However, over the course of the next years (post 2011), Google constantly overestimated flu prevalence. The reason for this is two-fold: on the one hand, the models became exceedingly complex relative to the small number of data points (over-fitting).

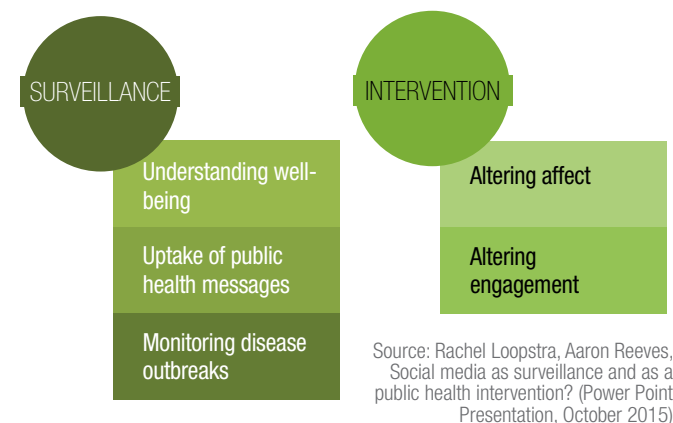
On the other hand, the algorithm increasingly suffered from an endogeneity bias, i.e. users' search behaviour was not only determined by their existing flu but by Google's search algorithm as well. Reeves concluded with a take-home message (referring to David Lazer's article): "We are far from a place where they [big data] can supplant more traditional methods or theories".

### Behaviour modification through Facebook and overcoming "slacktivism"

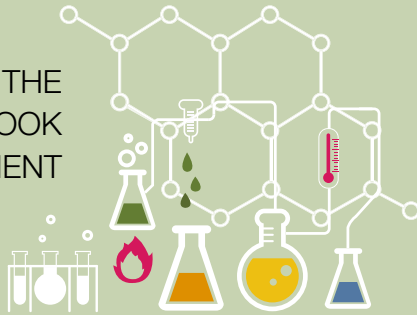
Subsequently, Reeves demonstrated some evidence on engaging people in specific actions through Facebook. By displaying how many of one's friends liked a page, one is more inclined to like that page as well and look at its content. The logical question is, however, whether "likes" on Facebook are enough to influence people's behaviour. In particular, the concept of "slacktivism" plays a key role here: people show their support by sharing or liking information, but no action or change in behaviour results as a consequence. Despite this concern, one U.S. study documented that actual voting participation increased when social network dynamics were smartly exploited. This result is of particular interest to certain public health interventions, such as vaccination mobilisation and dissemination of health information. For instance, more people could agree to get vaccinated when they see that their Facebook friends did so as well.

## OLD ETHICS FOR NEW DATA? - THE NEED FOR NEW ETHICAL FRAMEWORKS

Rebecca McKee, a Doctoral candidate at the University of Manchester, then spoke about the many ethical issues in using social media for health and healthcare research. She explained that naming Twitter users (via their Twitter handles) in published research - particularly prolific Tweeters who are usually linked to identifiable organisations - raises concerns about anonymity. Studies highly criticised for their ethics include the infamous "Facebook experiment", which sought to manipulate people's moods. And this in turn may have wider implications, with research showing that Twitter sentiment may even impact stock prices. McKee honed in on the wider implications of social media research, pointing out that there is a lack of a definition on what is ethically appropriate in social media research.



## THE FACEBOOK EXPERIMENT



"We show, via a massive (N = 689,003) experiment on Facebook, that emotional states can be transferred to others via emotional contagion, leading people to experience the same emotions without their awareness.

We provide experimental evidence that emotional contagion occurs without direct interaction between people (exposure to a friend expressing an emotion is sufficient), and in the complete absence of nonverbal cues."

When positive expressions were reduced, people produced fewer positive posts and more negative posts; when negative expressions were reduced, the opposite pattern occurred.

Source: Rebecca McKee, Ethical issues in using social media for health and healthcare research (Power Point Presentation, October 2015); from: Kramer et al. Experimental evidence of massive-scale emotional contagion through social networks. PNAS 2014

Old ethical frameworks do not seem to apply any more to current circumstances. For example, the inherent distance between the researcher and the subject makes it much harder to obtain informed consent. How do we ensure anonymity? What is public? What is private? Does having the default "retweet" function in Twitter automatically imply that something is in the public space? In conclusion, she reinforced the need for researchers and the general public to be aware of these ethical challenges and to act in a reflective manner.

### A HANDS-ON EXPERIENCE WITH NEW TOOLS

After the presentations, the audience was invited to participate in an interactive session on the Google Trends tool led by Aaron Reeves. In addition, Shu-Ti Chiou, Director General of the Health Promotion Administration in the Ministry of Health and Welfare in Taiwan, gave the audience a very insightful presentation on the current and progressive use of information and communication technology (ICT) in health promotion in Taiwan, including a vision of how ICT is going to be scaled up in the future. She informed the audience that the Ministry of Health is currently taking proactive measures and investigating alternative forms of information dissemination (social media) in order to reach and engage with more people. Her final message was that health policies should be based on "Promotion, Prevention, Protection and Participation!" - a slogan coined by Commissioner Andriukaitis that equally applies to European health policy-making.

Finally, the floor was opened for discussion. Several critical questions were posed by attendees, including the implication that excessively "digitising health" was incompatible with the current welfare state system.

We can take home three messages from this exciting session:

- Data collection has become a reality and will intensify in future. It is time for civil society, researchers and policy-makers to actively engage in this process for setting boundaries and improving healthcare.
- Social media has the potential to improve health surveillance and interventions. However, a number of methodological issues need to be resolved first.
- The use of new data sources, such as social media, raises several ethical concerns. New ethical frameworks need to be developed to guarantee a responsible use of new technologies.

■ Written by Dmitrij Achelrod and Deirdre Hickey ■

### FORUM 1

Organised by Health Promotion Administration,  
Ministry of Health and Welfare, Taiwan R.O.C.

in cooperation with

London School of Hygiene and Tropical  
Medicine, UK





# The power of data

The cutting edge of technological advances being used to understand health and health behaviours

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This second session, moderated by Harry Rutter, Senior Clinical Research Fellow at the London School of Hygiene and Tropical Medicine (LSHTM), started with a brief overview of novel uses for “Big Data”. Nowadays, intelligent apps tracking physical activity and calorie burn are quite accurate in monitoring walking, cycling and other activities. In a world where obesity is such a challenging public health issue, promoting physical activity during the day can expend substantial amounts of calories, opening up a myriad of opportunities for strengthening healthcare systems and improving people’s health. His presentation also introduced the concept of the “quantified self”, the idea of measuring one’s daily activity from an individualised perspective using technology aids, which is being increasingly used by the industry for commercial purposes. For example, health insurance companies might want to keep track of how active their clients are, which in turn influences their risk exposure and, ultimately, premiums. Other data uses include reviewing doctors or other professionals, as well as giving feedback to services received. This “democratisation of information” has interesting possibilities, but can also be taken advantage of by unscrupulous individuals.



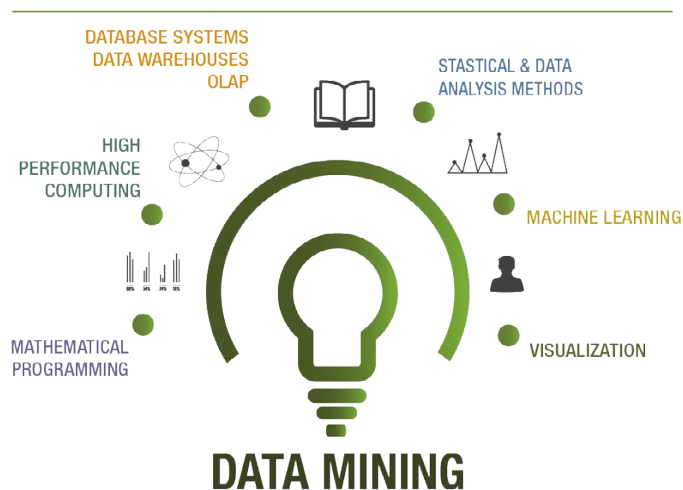
## LOOKING INSIDE YOUR SHOPPING BAG: THE USE OF RETAIL DATA TO CAPTURE HEALTH LIFESTYLES

Ben-Chang Shia, Director of the Big Data Research Center and School of Management at Taipei Medical University, subsequently made the case for Big Data as a transformative concept that may change the way we view science. He gave a biological perspective to big data, citing the proliferation of biobanks in recent years as an example of how biotechnology permits the use of micro-arrays and existing databases to foretell disease risk. The SMAC (Social, Mobile, Analytics and Cloud) acronym is a useful one to keep in mind to remember the main areas of big data, which are experiencing exponential growth due to increasing computing speed and storage capacities. There are a number of areas included within the broad term “Data Mining”, but the ultimate aim is to deploy data collected and understand it. Shia elaborated on the National Digital Database for the media which exists in Taiwan to allow for study of media (text, voice, images), and briefly described the National Health Insurance Database, which offers easily-accessible patient profiling, drug and medicine disposition and so on. All this data can be linked with other databases for further analysis, and a number of publications making use of NHIRD data demonstrate its potential impact. Another interesting facet of Big Data is the use of retail data to capture information about lifestyle. Marketing is a powerful tool, and combining information consumer behaviour, strategic

marketing and supply chains can be a powerful way of improving marketing strategies. The applications of Big Data range from the deciphering of the human genome to the quantification of the physical ecosystem. Although exciting, how can big data in practice be used to drive change in healthcare? As Shia stressed: “Knowing is not enough, you must apply it [knowledge]”. This is why Taiwan has invested heavily in the development of modern technological infrastructure. For instance, one of the many projects presented in the session aims to use data analytics to provide valuable insights and actionable recommendations for individual and population health, supported by a cloud database that will map information such as personal medical diagnoses, real-time vital parameters, drug prescriptions, socio-economic and environmental variables. Patients, physicians and public health experts will receive support in decision-making to maximise health benefits. Powerful machine learning algorithms and harmonisation of data reporting will be required to master this ambitious project. Shia concluded by mentioning that storing sensitive information on cloud servers bears the risk of data theft and inappropriate use, hence safety and security should be kept in mind.

### HEALTH FROM ABOVE: INNOVATIVE USES OF SATELLITE IMAGING

Chris Grundy, Lecturer in Geographical Information Systems at LSHTM, subsequently demonstrated some practical applications of modern imaging technology and web applications in research that are used to obtain data quickly and efficiently from data-poor settings. Maps have been used for centuries, but the advent of social media and smartphones have drastically altered public health mapping. Opportunistic data collection arises from the fact that we have these tools in our pockets, and we can use these to collect data for us in different ways. Smartphones featured prominently in his presentation, as he demonstrated how running simple GPS-locating apps on smartphones allowed researchers to map villages and track infectious disease outbreaks. Aside from geo-located photos, very high-resolution (VHR) satellite imagery was also used to cheaply estimate population density within hours, as opposed to the weeks usually required to obtain an expensive estimate using classical survey head-counts. Crowd-sourcing is also a novel way of collecting information (OPENSTREETMAP as an example).



Source: Ben-Chang Shia, Six Aspects of Data Mining (Power Point Presentation, October 2015)

Ketevan Glonti, Research Fellow at LSHTM, then presented her work on the SPOTLIGHT project – “Sustainable Presentation of Obesity through Integrated Strategies”, which aims to address social and environmental determinants of obesity in order to provide evidence to influence policy makers at the local, national and European level to create better living environments. Her research involved exploring the obesogenic environment in Greater London using the Google Maps virtual audit tool, evaluating several London neighbourhoods regarding factors that could promote or prevent healthy lifestyles. For instance, a street with plenty of fast-food restaurants, no cycle lanes and few green leisure areas would be considered conducive to unhealthy behaviour – or obesogenic. Using virtual auditing tools such as Google Maps allows researchers to conduct such evaluation more quickly, easily and cheaply than with traditional, on-site research methods.

Building on what was said earlier, Ben-Chang Shia took the floor once again to outline how data is being used in Taiwan to identify and map areas having the highest BMI: the Taiwanese web-based GIS Obesity Surveillance System for monitoring obesogenic environments. The towns with the highest BMI are the more rural, isolated, disadvantaged areas. GIS and Google Street View (GSV) data can be combined with healthcare variables in order to visually demonstrate what can be contributing to the high BMI or other diseases, and lead to an understanding of the obesogenic environment that in turn enables better policy decisions to be

taken. This was followed by a demonstration on the use of GSV in a typical urban street in Taiwan by Andrew Barnfield, Research Fellow at LSHTM, who led forum participants virtually through the street, highlighting potentially obesogenic factors.

Finally, several interesting points were raised during the plenary discussion. The issue of Big Data transparency was raised (where do the data come from, how were they analysed and are they made available to other researchers)? Europe is in a situation where use of Big Data is becoming ever more prohibitive due to data privacy concerns. How was the idea of Big Data sold to the public in Taiwan, how come they are so accepting of it? Ben-Chang Shia answered that the information generated is totally open, it is useful to the public and can be used in apps, etc. People are also typically interested in information that is relevant and of

interest to their lives (e.g. What are the healthier restaurant choices around them? Where can they walk?), and this helpful, supportive information is built into the results/apps. Thus, a participatory way is applied to help integrate use (and acceptance) of data.

A query on how the data collection can be replicated, including how the SPOTLIGHT data protocol will be shared, resulted in a tribute to E. Deming's phrase "In God we trust; all others must bring data". Another issue raised by a Taiwanese delegate was that conducting an audit may be challenging if one is not familiar with the area under assessment, which led to an interesting discussion on scalability of doing a virtual audit, and whether algorithms could be developed to audit the environment automatically. Harry Rutter clarified that auditing is useful in finding patterns: a high quality environment is a necessary component but not sufficient in itself.



Ketevan Glonti, Andrew Barnfield, Ben-Chang Shia

■ Written by Daniel Cauchi and Jonilda Sulo ■

## FORUM 1

Organised by Health Promotion Administration,  
Ministry of Health and Welfare, Taiwan R.O.C.

in cooperation with

London School of Hygiene and Tropical  
Medicine, UK





# Modern healthcare

## My health, my responsibility

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Terje Peetso, Policy Officer, Health and Well-being Unit, DG CONNECT, European Commission, opened the session with the strong statement that the patients of today want to take responsibility for their own health. One important question that rises in this context: “How can digital tools help people in this process?” After her introductory speech Peetso introduced the panel, comprising representatives from different sectors, and noted that the topic of self-responsibility usually generates lots of questions.

The EC has published an eHealth Action Plan 2012-2020 and this roadmap outlines the vision for eHealth in Europe. Patients with chronic health conditions spend a significant amount of their time outside the formal healthcare system, self-managing their disease, and there is a potential for eHealth to be used even more to support this. There are many apps available today measuring different parameters of health, e.g. blood pressure; in the future we might see more healthcare apps that actively support self-management.

The audience was united in their opinion that health literacy is the most important issue to address if we want citizens to manage their own health, with the help of technology. It was also interesting to reveal that the majority of the audience had not looked at their own medical data online; we can all benefit from improving our knowledge on and agency over our own health.

Benny Eklund, Member of Uppsala County Council, which provides healthcare services to the citizens of the county in Sweden, shared his experience from the CIP-funded project Sustains. The project addressed the following topics:

- Empowerment of patients: there is a growing tendency by patients and the public to question information from the health system, ask for a second opinion, demand respect and dignity in their treatment, and expect convenience
- Quality of care: new progress in healthcare means that patients demand, and healthcare professionals want to offer, the best quality of care
- Efficiency: there is growing demand from patients/citizens for improved efficiency in health care funding and delivery

When the Uppsala County Council introduced online access for citizens to their Electronic Health Record (EHR) there was resistance from the caregivers who did not think patients could cope with the responsibility. Patients, on the other hand, accessed the information as soon as the opportunity arose. As one cancer patient put it: “Yes, it is scary to get the information, but ignorance is not the solution”. This case study, on giving patients access to their EHR, shows us that the patient doesn’t have to do everything, but is able to do a lot regarding the management of their condition, if you give them the chance.



## PATIENT EMPOWERMENT

Ana M Carriazo, Senior Advisor, Regional Ministry of Equality, Health and Social Policies of Andalusia, Spain, reported on the results of the PALANTE project. The PALANTE project focused on the implementation, scale-up and optimisation of seven pilot sites, trialling secure and user-friendly access to online personal medical and health data by the local patient population. The pilot sites were able to test different types of online healthcare service offered. As a result, the project found that there were different levels of patient empowerment across the different sites. A Patient Activation Measure was used to measure patients' roles in managing their health. Interestingly, the interventions did not generate a significant increase in patient involvement and this was explained by the fact that patients at the pilot site were already actively involved in their own healthcare plans. The project found that patient activation depends on:

- Level of trust in the healthcare system
- Previous patient experience
- Perceived and experienced usability of the e-services provided

The patients' perspective was provided by Johan G Beun, Manager, AdrenalNET, The Netherlands. AdrenalNET is an organisation where patients, healthcare practitioners and informal carers have the opportunity to virtually meet up and share their experience, knowledge and ideas about care for patients with adrenal gland disorders. Numerous examples of what the network has achieved so far were given including: information to patients and caregivers; bottleneck analysis to improve care pathways; ambulance protocols and an emergency card (which has also been exported to other European countries).



Johan G Beun, Angela Brand and Edwin Maarseveen

## “BEST GOVERNANCE” FOR CITIZEN DATA

Angela Brand, Maastricht University, the Netherlands highlighted the importance of the principle of subsidiarity. The principle of subsidiarity is fundamental to the functioning of the European Union, and more specifically to European decision-making. In particular, the principle determines when the EU is competent to legislate, and contributes to decisions being taken as closely as possible to the citizen. Brand stressed not only the implications that this principle has with respect to the core responsibility of governments, but also its civic dimension, as it increases the opportunities for citizens to take action. In her presentation, Brand further highlighted the potential for personalised medicine to advance holistic and person-centred approaches to care. She argued that an individualised approach, based on patient level data gathered throughout the life-course of an individual patient, could result in consistent improvements in health outcomes. Personalised medicine could also allow more detailed comparisons between individual patients, potentially supporting practitioners to identify the most appropriate treatment and management regime for their patients.

However, personalised medicine raises many questions around data governance. Currently companies such as Google are taking advantage of Big Data; the new economic asset. Brand argued that a system allowing citizens to control their own data and health records must be structured within a robust information handling system. What are the gains for patients? Brand argued it certainly shouldn't be in monetary terms. Citizens should instead have the opportunity to contribute to civil society through the provision of data as a public good. For example, the gains from data sharing could be directed towards the construction of a hospital or care model. This approach would not only lead to a reduction in social inequalities but also, by putting the citizen in the driver's seat, would foster the realisation of the full potential of personalised medicine. Such an approach is employed by cooperatives like MIDATA that promote the idea of common good within and beyond the health sector; an approach in which the citizen is the main stakeholder.

## ORGANISATIONAL CHANGE SHOULD ACCOMPANY eHEALTH INNOVATIONS

Edwin Maarseveen, Project Manager for eHealth at the Ministry of Health, Welfare and Sports in the Netherlands and a Young Forum Gastein Scholar, stressed that when dealing with eHealth and ICT we must take into account the changes that they bring to an organisation: “If expensive technology is added to an old organisation, the result is often that you get a costly old organisation”. Organisational change should accompany eHealth innovations.

Maarseveen stressed the importance of involving patients in the design of eHealth solutions, and that engagement can be fostered in a number of ways. He gave the example of the “eHealth week”, an event that will take place from 8-10 June 2016 in Amsterdam, which aims to involve and engage patients through a number of innovative approaches.

Despite putting the patient at the centre of their health plan with digitalised solutions, we must nonetheless remember that this is a complement for, not a replacement of, care by medical professionals. A digitalised society brings about rapid change at



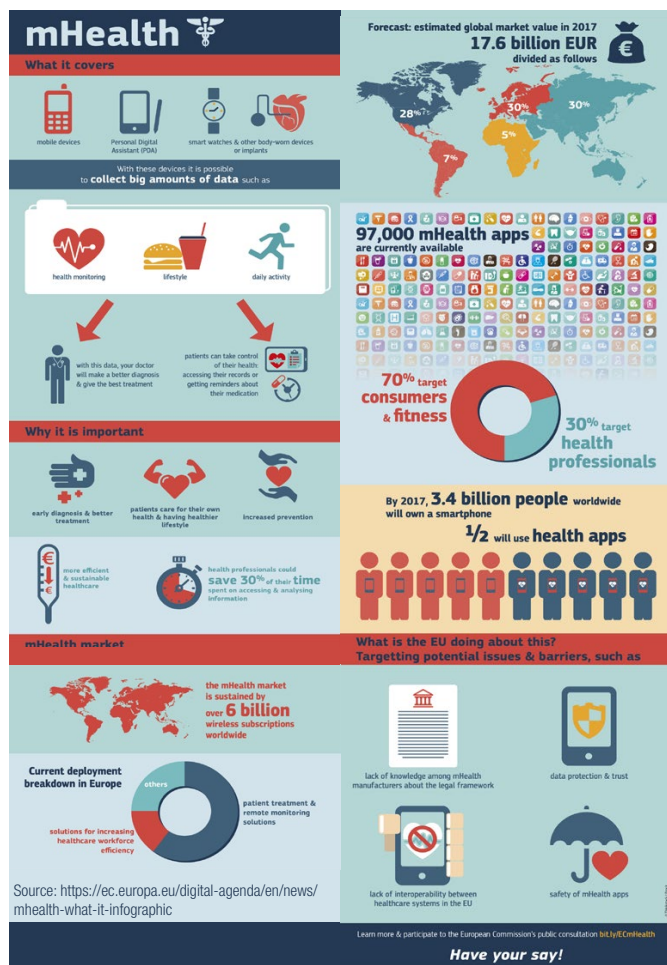
Benny Eklund, Ana M Carriazo and Johan G Beun

a pace that governments need to keep up with. This should be paired with a focus on incremental changes and a tailoring of the system that will support innovation.

## CONCLUSIONS

The concluding discussion raised the question of what the role of the EC should be when it comes to eHealth solutions. Beun stated that in his opinion, its role is to ensure standards and semantic interoperability. Peetso explained that currently the EC has two major working groups in this area: one working on data handling and the other one on the reliability of data and how data is linked. Another point made was about citizen health literacy. This was considered an important aspect that needs to accompany eHealth solutions. Lastly, going back to the principle of subsidiarity, the session concluded that the decision to bring about change is made at the level and context where it has the best effect. Therefore we have a responsibility as a society to enact change and not rely solely on institutions.

■ Written by Ioana Ghiga and Maria Söderlund ■



## FORUM 7

Organised by DG Communications Networks, Content and Technology (DG CONNECT), European Commission





# Modern healthcare

mHealth is a solution (not a problem)

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This session brought together a diversity of speakers in the field of health and technology, users, doctors, industry and policy-makers, to provide different perspectives on how eHealth contributes to their everyday practice. How can patients and stakeholders best take advantage of eHealth and take greater control of their health and disease management?

Today, there is a profusion of mobile applications (apps) available that relate to health and well-being. This arguably reflects the growing interest in paying greater attention to our health and health management, and the fact that this can be achieved through use of mobile technology. However, there are many issues to be debated regarding the use and storage of personalised health data, the reliability of some mobile health apps, and codes of conduct... to name but a few.

## HOW CAN STAKEHOLDERS RESPOND TO THE eHEALTH CHALLENGE?

Michal Boni, Member of European Parliament (EPP, Poland) talked about new technologies, including mobile apps as game changers in healthcare. At present, the priority lies with how to combine two paradigm shifts: 1) realising opportunities to develop a more patient-centred system whilst 2) managing and preventing any negative impacts through misuse of this new technical environment.

Given the likely primacy of eHealth in future healthcare solutions, equal focus must be given to issues of online access, digital literacy and understanding of digital tools. Patients and the public need infrastructure to support every-day use of eHealth tools.

There needs to be provision of clear standards and controls from the centre. Digital literacy is a key factor to increase efficiency and personalise medical services. This so-called market demand will be stimulated only if there is the right technology and the right structures in place to use it.

All of this has implications for the platforms upon which Big Data is exchanged. It was stressed that sensitive data that needs to be protected against unauthorised use and access. Co-operation among stakeholders across government, industry and society is crucial. Privacy and security constitute the two aspects of the same coin.

## REGULATORY VS. NON-REGULATORY

Patients and consumers should be at the heart of the mHealth framework. At present, two issues still need to be balanced and addressed: on one hand, there is a lack of rules in new areas of mHealth giving rise to uncertainty over jurisdiction, governance and operations; on the other, there is a potential to overburden the system with regulation. The right balance should protect consumers and patients. This could be achieved through soft laws,

guidelines, codes of conduct on mHealth and adequate certification schemes in an accessible, simple and understandable way.

All stakeholders need to be involved to guarantee a successful outcome that involves assessing benefits and cost-effectiveness.

Ehealth can be part of effective healthcare systems by providing simple tools to measure health status, build trust between patients and healthcare professionals, and promote responsibility self-management. The European Parliament is currently very active in the Digital Strategy Agenda.

### HOW mHEALTH CHANGED THE HEALTHCARE SYSTEM IN IRELAND?

Ireland recently underwent reform to respond to an ageing population, a rise in chronic conditions, and an increasing demand for healthcare; common challenges experienced across Member States. The health ministry joined forces with healthcare community stakeholders to “aspire to give a world class title” to their citizens, highlighted John Farrell, Ministry of Health, Social Services and Public Safety of Northern Ireland.

Modern healthcare system reform requires an approach that will tailor services to patient needs and technology has a role to play here. Technology can support workforce organisation and care delivery, for example through enabling doctors to access electronic patient records and increase the safety of care for patients.

Technology can change the way patients are monitored, and can therefore facilitate the delivery of healthcare at home even for patients who would previously have required hospitalisation.

The integration of eHealth into the national care strategy in Northern Ireland provides a number of learning points:

- Support electronic access to patient information for patients and practitioners
- Use information to support knowledge on personalised care
- Foster innovation in partnership with international partners
- Maintain and improve modern and reliable e-health infrastructure
- Healthcare apps should ensure sustainability

Farrell concluded with Nelson Mandela’s quotation “Vision without action is just a dream, action without vision just passes the time, and vision with action can change the world”.

### TRUST, SECURITY AND SAFETY IN MODERN HEALTH

Jeremy Wyatt, Adviser on New Information and Communications Technologies, Royal College of Physicians provided a comprehensive overview of the recent evidence on privacy and mHealth apps, from the Huckvale et al 2015 study of 79 accredited lifestyle apps from the NHS Apps library. It outlined that only 67% had a privacy policy, no app encrypted data held on the device and 89% leaked confidential data over the network. Infrastructure is needed to provide mHealth users with a secure framework to use apps appropriately and safely.

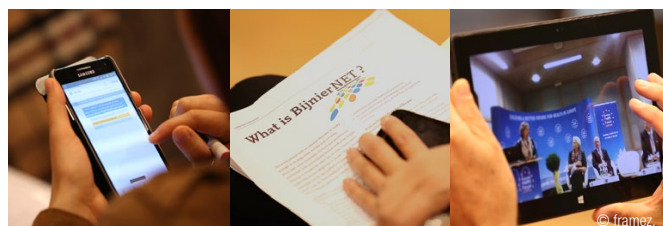
Wyatt reiterated that a new approach is required for further progress of mhealth including:

- Users’ self-determination
- Prevent bad apps, help app developers understand safety and quality
- Self-regulation by developer community
- Quality is best achieved by consensus and culture change
- App innovation must balance benefits and culture change
- App innovation must balance benefits and risks

To learn more on this topic, a paper will be released soon by the UK Royal College of Physicians addressing 17 questions designed for clinicians on what to know before using an app.

### HOW DOES THE INDUSTRY VIEW mHEALTH?

Michele Pastore, Electronics and Code of Conduct Working Group, Samsung, shared Samsung’s insights in dealing with technology with a focus on apps. The company took part in a joint development process initiated by the European Commission to jointly draft a Code of Conduct with a range of stakeholders from civil society. The process addressed usability, market access and international cooperation. The Code of Conduct will cover purpose, scope (including marketing and advertising), conditions of adherence, data protection, security requirements and governance.



## PATIENTS' PERSPECTIVE

Nicola Bedington, Secretary General, European Patients' Forum (EPF), provided the EPF perspective on mobile health, connectivity and patient empowerment. There is a fundamental link between the use of eHealth and mHealth technology and patient empowerment. ehealth and mhealth are key enablers for patient empowerment. In turn, patient empowerment is key to secure appropriate, safe and effective use of ehealth and mhealth technologies.

Patient empowerment is defined by an EPF campaign with the five "E"s, namely:

- Education: patients can make informed decisions about their health if they are able to access all the relevant information
- Expertise: patients self-manage their condition every day so they have unique expertise on healthcare which needs to be supported
- Equality: patients need support to become equal partners with health professionals in the management of their condition
- Experience: individual patients work with organisations to represent them and channel their experience and collective voices
- Engagement: patients need to be involved in designing more effective healthcare for all and in research to deliver new and better treatments and services

AND THIS BUTTON  
TURNS ON THE  
RESPONSIBILITY BLOCKER!



UPDATE  
FEATURES...



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EPF is an active partner in different projects covering eHealth/mHealth understanding such as SUSTAINS and EUPATI where patient knowledge, control and shared decision-making are at the heart of the process.

## TAKE HOME MESSAGES

- Studies overwhelmingly suggest patients are willing to play an active role in managing their own condition, and that healthcare professionals are willing and ready to use eHealth technologies
- eHealth and mHealth are key components of a patient-centred approach, essential for prevention and health promotion and can be supportive in managing a long-term conditions. These have to be developed in a holistic manner, including wide consultation of healthcare community stakeholders
- There is great variation in the quality and safety of mHealth tools. Some clear quality criteria should be set and used to publicly evaluate and label apps.
- There are unanswered questions around the processing and ownership of data. Clear efforts from government and industry are needed to take progress forward

■ Written by Ioannis Natsis and Clara Zachmann ■

## FORUM 7

Organised by DG Communications Networks,  
Content and Technology (DG CONNECT),  
European Commission







# Beat the silence

Harnessing the full potential of EU society to ensure growth through inclusion of the disabled

Fuelled by the strap line “Harnessing the full potential of EU society to ensure growth through inclusion of the disabled”, a highly stimulating debate took place during the morning workshop session organised by MED-EL, moderated by Peter O’Donnell from POLITICO. The high-level panel invited on this occasion consisted of: MEP Karin Kadenbach (S&D, Austria), representing the political pillar, Iain Bruce from the Royal Manchester Children’s Hospital (UK), presenting the medical perspective, Ingeborg Hochmair, the Co-Founder and CEO of MED-EL, offering insights from industry, and as the “Voice of the Patients” Helena Martins, who spoke from personal experience, but is also Head of Digital Engagement at the UK’s National Deaf Children’s Society.

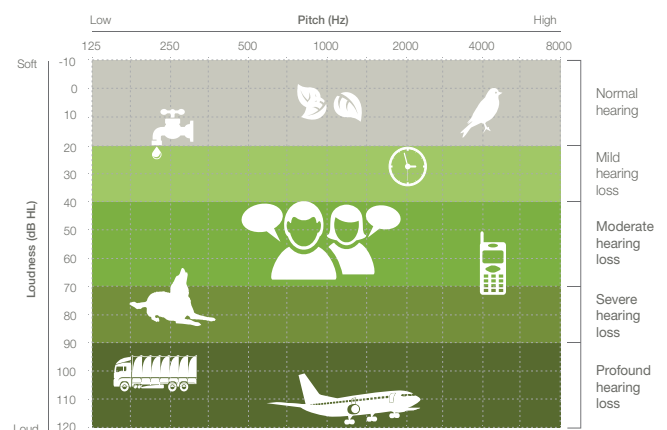
As indicated in Peter O’Donnell’s introductory words, this session highlighted a particularly successful case, where the business and the medical worlds have come together in synergy to solve a particular experience of disability, or as articulated later in the workshop, an “invisible disability”.

According to WHO estimates, as many as between 0.5 to 5 in every 1000 children worldwide are born every year with hearing impairment or develop it later in life. Even though hearing impairment is often dubbed “invisible”, this condition heavily impacts on children’s development and significantly diminishes their potential to live an unrestricted and productive life.

Iain Bruce elaborated on this and the severe consequences that impaired hearing has on a child’s speech understanding, speech production, reading ability, general educational advancement and cognitive development.

As a paediatric otolaryngologist, Bruce told the audience about the relative simplicity of certain surgical procedures to correct loss of hearing. For example, with the surgical implantation of an electronic device into the inner ear, children can usually leave the hospital the same day. He stressed the importance of early detection and surgical correction of hearing impairment in order to safeguard children’s development.

AUDIOGRAM ILLUSTRATING USABLE HUMAN HEARING



Source: Switched on for life - European report, HEARING network  
<http://www.hearing.com/wp-hearing/de/news-posts/switched-life/>

Bruce presented data showing that children’s speech, language and cognitive development are greatly enhanced when hearing impairment is detected and corrected early. This can lead to improved educational outcomes and career opportunities, ultimately leading to higher quality of life and psychological well-being. On the other hand, if children, or adults for that matter, continue to suffer with auditory disability, this can lead to anxiety, perceived stress and even severe depression.

### “HELP THOSE WHO HAVE TO LIVE A DIFFERENT LIFE IN ORDER TO BE INCLUDED”

Regarding denial or restricted access to procedures to correct hearing loss, Peter O’Donnell called on Karin Kadenbach to discuss the regulatory side in her introductory statement. Having been actively engaged in political health issues for many years, she more than ever strives to “help those who can be helped and help those who have to live a different life in order to be included”. Hence, she quoted Article 168 of The Lisbon Treaty, which states that “A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities”. Moreover, it states clearly that all actions “shall be directed towards improving public health, preventing physical and mental illness and diseases, and obviating sources of danger to physical and mental health”. She highlighted how enabling access to hearing loss correction procedures clearly aligns with the message of the Treaty.

Kadenbach stressed the importance of taking action and also of acting together. She emphasised how investing in health is about investing in Health in All Policies, and that solidarity across

Europe needed to achieve this. Despite hearing loss having not just personal costs but also significant economic costs, access to treatment is variable across Europe. The total cost for untreated hearing impairment in the EU is estimated to amount to around €224 billion per annum (i.e. medical costs, costs for special training and rehabilitation, productivity losses). However, it may depend on where one is born if one has access to a fully approved medical device, such as the cochlear implant produced by MED-EL. Furthermore, in many European countries only a single cochlear implant is funded; patients are not entitled to both even if hearing is impaired in both ears.

### BEAT THE SILENCE - USER’S VOICE

Securing health in Europe by securing adequate and universal access to this approved hearing loss technology was therefore agreed by the panel to be a cornerstone of strategic planning for successful health system strengthening.

“Beating the silence” is what was actually achieved by Helena Martins, a patient who has suffered from acute and total hearing loss as an adult herself. Being the “voice of the patient”, she gave a passionate speech about her own frustrating experiences up to the point when she was lucky enough to get a cochlear implant. Today she is the Head of Digital Engagement at the UK’s National Deaf Children’s Society. She emphasised that people are completely clueless concerning how to speak to deaf people and awareness is critical to lower the immense barriers for children as well as adults facing this disability.

Ingeborg Hochmair, a pioneer in the development of the world’s first micro-electronic multichannel cochlear implant, gave an overview of MED-EL. MED-EL, as a globally active company, aims to restore hearing impairment by offering a set of hearing implant solutions. The latest generation of hearing implant solutions do not even look like classic hearing aids. The developers make every effort to design them so they blend into daily life. Conveniently the audio processor, which is the device on the outside, is the part that can be improved and upgraded easily without additional surgery. Patients who already have a device can benefit from the most recent and innovative improvement. As a strategy to remove barriers to hearing healthcare and achieve the essential early implantation and hence unrestricted development of children,



Helena Martins,  
Iain Bruce  
Karin Kadenbach and  
Ingeborg Hochmair  
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she called for widespread hearing screening of newborns in order to enable detection of congenital severe hearing loss. She emphasised hearing as a crucial basic sense and identified hearing healthcare as a fundamental right for all children, and hence stated that the company plans to work even harder to eradicate hearing impairment as one of the leading causes of disability in Europe and worldwide. Moreover, as Kadenbach pointed out, in terms of securing health we should also not forget demographic changes and the importance of intact hearing as a vital factor for healthy ageing. Bruce also noted that there really is no age limit for receiving such an implant.

Rounding up a highly interesting and inspiring workshop, action plans were formulated for helping those suffering from this “invisible disability”, which affects 32 million children worldwide every year, not to mention the elderly experiencing hearing impairment. All panel members agreed unequivocally that raising awareness is key to increasing access to this life-enhancing technology. In addition, further reducing health inequalities and increasing access to hearing implants, ultimately leading to a more productive life, can only be reached by initiating and promoting an elaborate intervention composed of: training, awareness, access and rehabilitation.

■ Written by Martina Überall (Naschberger) ■



1. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.

Union action, which shall complement national policies, shall be directed towards improving public health, preventing physical and mental illness and diseases, and obviating sources of danger to physical and mental health. Such action shall cover the fight against the major health scourges, by promoting research into their causes, their transmission and their prevention, as well as health information and education, and monitoring, early warning of and combating serious cross-border threats to health.

The Union shall complement the Member States' action in reducing drugs-related health damage, including information and prevention.

2. The Union shall encourage cooperation between the Member States in the areas referred to in this Article and, if necessary, lend support to their action. It shall in particular encourage cooperation between the Member States to improve the complementarity of their health services in cross-border areas.

Member States shall, in liaison with the Commission, coordinate among themselves their policies and programmes in the areas referred to in paragraph 1. The Commission may, in close contact with the Member States, take any useful initiative to promote such coordination, in particular initiatives aiming at the establishment of guidelines and indicators, the organisation of exchange of best practice, and the preparation of the necessary elements for periodic monitoring and evaluation. The European Parliament shall be kept fully informed.

3. The Union and the Member States shall foster cooperation with third countries and the competent international organisations in the sphere of public health.

4. By way of derogation from Article 2(5) and Article 6(a) and in accordance with Article 4(2) (k) the European Parliament and the Council, acting in accordance with the ordinary legislative procedure and after consulting the Economic and Social Committee and the Committee of the Regions, shall contribute to the achievement of the objectives referred to in this Article through adopting in order to meet common safety concerns:

(a) measures setting high standards of quality and safety of organs and substances of human origin, blood and blood derivatives; these measures shall not prevent any Member State from maintaining or introducing more stringent protective measures;

(b) measures in the veterinary and phytosanitary fields which have as their direct objective the protection of public health;

(c) measures setting high standards of quality and safety for medicinal products and devices for medical use.

5. The European Parliament and the Council, acting in accordance with the ordinary legislative procedure and after consulting the Economic and Social Committee and the Committee of the Regions, may also adopt incentive measures designed to protect and improve human health and in particular to combat the major cross-border health scourges, measures concerning monitoring, early warning of and combating serious cross-border threats to health, and measures which have as their direct objective the protection of public health regarding tobacco and the abuse of alcohol, excluding any harmonisation of the laws and regulations of the Member States.

6. The Council, on a proposal from the Commission, may also adopt recommendations for the purposes set out in this Article.

7. Union action shall respect the responsibilities of the Member States for the definition of their health policy and for the organisation and delivery of health services and medical care. The responsibilities of the Member States shall include the management of health services and medical care and the allocation of the resources assigned to them. The measures referred to in paragraph 4(a) shall not affect national provisions on the donation or medical use of organs and blood.

The Lisbon Treaty

Treaty on the Functioning of the European Union and comments,  
Part 3 - Union policies and internal actions, Title XIV - Public health (Article 168)

WORKSCHOP 10

Organised by MED-EL Medical Electronics

**MED<sup>o</sup>EL**







# ACCESS TO TREATMENT

WORKSHOP 4  
MAPPs.  
New paths  
to personalised medicine

FORUM 6  
Access to new medicines  
in Europe

WORKSHOP 5  
Equity and solidarity in EU  
healthcare systems

FORUM 9  
Access to high-quality  
healthcare  
and innovative treatment

LUNCH  
WORKSHOP 2  
Measuring “value”

part V

# Access to new medicines in Europe

High-priced medicines. Affordability and sustainable access

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In this forum the audience was introduced to various perspectives on access to medicines, with representatives from public health, clinical oncology, pricing and reimbursement, patients, payers, regulation and health technology assessment (HTA).

## PRINCIPLES FOR THE APPROPRIATE USE OF MEDICINES AND CURRENT CHALLENGES

The forum was opened by Hans Kluge, Director, Health Systems and Public Health, World Health Organization Regional Office for Europe, who described access as one of the most topical and timely issues in healthcare at the moment.

The number of new medicines receiving marketing authorisation annually has increased dramatically in recent years, particularly in oncology. Drug sales are projected to grow at a rate which greatly exceeds the budget increases of healthcare systems. This trend has put strain on health systems who must find a reasonable balance between rewarding meaningful innovation, equitable and affordable access and sustainable health systems. Solutions to this challenge require collaboration and information sharing, and must involve all stakeholders. Kluge identified opportunities for planning and managing costs in the pre-launch, peri-launch and post-launch phases of a product life-cycle including horizon scanning, HTA, price negotiations, risk-sharing, appropriate/responsible use and affordable access for those who need it.

## MEDICINE PRIORITISATION AND NEW CANCER DRUGS IN EUROPE

The clinical oncology perspective was provided by Alexandru Eniu, Board Member and Chair of the Emerging Countries Committee, European Society for Medical Oncology (ESMO).

Eniu stated that there are considerable disparities in cancer treatment outcomes across Europe. A recent study documented that the relative survival for breast cancer, prostate cancer, and melanoma is considerably lower in some eastern European countries compared to their northern neighbours. Amongst the key reasons for this are differences in health systems, overall health of the population, lifestyles, cancer programmes, health workforce, and pharmaceutical treatment. In the triangular relationship between health professionals, pharma and national bodies, all three have a role to play. Pharmaceutical companies have dramatically increased prices creating problems for access. National bodies may be responsible for inconsistent reimbursement strategies as they are facing limited resources. Health professionals have not raised the bar high enough in terms of the benefits demanded of expensive new drugs. Eniu illustrated the considerable variability in access to cancer medicines across Europe, including drugs listed on the World Health Organization Essential Medicines list. This list includes inexpensive drugs which are still not available in some EU countries. The European Medicines Agency (EMA) tests new drugs for safety and efficacy

and approves for all of Europe, but there are 28 different systems of reimbursement. Eniu suggested that national authorities and HTA bodies work with weak data and replicate the same assessment performed by the EMA at a lower level. The issue of medicine shortages of several older, effective, and inexpensive drugs needs to be tackled, to improve treatment for patients without putting strain on limited resources.

## CANCER MEDICINE AS A CHALLENGE FOR PUBLIC PRICING AND REIMBURSEMENT

Sabine Vogler, Gesundheit Österreich GmbH, Head of the WHO Collaborating Centre for Pharmaceutical Pricing and Reimbursement Policies, presented the results of a survey of decision-makers in European countries aimed at collecting information on pricing and reimbursement policies of new premium-priced medicines. This survey was conducted as part of the WHO report on Access to New Medicines in Europe (2015). Responses were received from 27 countries within the Pharmaceutical Pricing and Reimbursement Information Network (PPRI) network. Notable results included the lack of an explicit definition of high cost medicines or specific rules for pricing and reimbursement of oncology medicines, and the increasing use of HTA and price negotiations. Managed entry systems are increasingly playing an important role in oncology ensuring access to medicines, particularly those with limited cost-effectiveness. Such systems can however lead to reduced transparency as the content is often confidential. Horizon scanning was found to play a limited role in most European countries.

The results of a second survey were also presented. This survey



Lieven Annemans, Maria Iglesia, Alexandru Eniu  
Nicola Bedlington, Josef Probst and Sabine Vogler

investigated which policy mix, related to the reimbursement of medicines, stakeholders would consider as ideal. External price referencing (EPR) was considered to have the lowest ability to achieve the different policy objectives, together with differential pricing (DP) and “discounts / rebates / negotiations / claw-back”. Possible reasons for the low rank of EPR included the practice of referencing the official list prices instead of actual discounted prices, the unfairness of the system and availability issues which may arise contributing to medicine shortages. Despite these limitations EPR is still widely used as it is “easy”, although resource-intensive and may produce short-term savings. EPR will continue to be used due to a perceived lack of alternative pricing policies, as there is a lack of acceptable alternatives.

## UNDERSTANDING PATIENT-SIDE DEMAND FOR MEDICINES

Nicola Bedlington, Secretary General, European Patients' Forum, also highlighted huge disparities among EU Member States in access to both basic healthcare and innovative treatments. As a result, patient organisations fight for equality and solidarity based healthcare provision.

From her point of view, political will and leadership has been demonstrated in recent years. There are several instruments in place like the WHO Report Priority Medicines for Europe and the World and Adapt Smart, a platform for the coordination of Medicines Adaptive Pathways to Patients (MAPPs) activities.

One example Bedlington discussed was the Patient Access Partnership (PACT), a patient-led multi-stakeholder network bringing together patients, the medical and public health community, industry and the European and member states policymakers and institutions. Its purpose is to develop and move forward innovative solutions to reduce inequities in access to quality healthcare in the EU through patient involvement. From a patient's perspective, greater transparency on pricing mechanisms and everything that influences “the final price tag” is needed. Bedlington also called for the exploration of meaningful alternatives to external reference pricing such as value based pricing, taking into account the proven benefit for the patients. She closed by underlining that patients are a part of the solution and need to be part of the change process.

## PANEL DISCUSSION

Following the main speakers, a panel discussion was held on the ethics, legal and economic issues of high-priced medicines and future sustainability. The discussion was moderated by Jack Scannell, Centre for the Advancement of Sustainable Medical Innovation (CASMI) and Innogen Institute, University of Edinburgh, UK.

Josef Probst, Director General, Main Association of Austrian Social Security Institutions, stated that some drugs have clear added value, but for others the value is questionable. The high degree of public-sector support for drug companies raised further ethical questions. Is it right for companies to charge such high prices, while benefiting from public support for basic science, from drug markets largely financed by nation states, and while, in some cases, aggressively “optimising” their tax strategies? The need for a second ceiling, not only value based pricing but ethical pricing including the dimension of costs, was proposed. Compulsory licensing was also suggested as well as a reduction in the length of pharmaceutical patents, when the investment has rapidly amortized. Probst made a strong call for transparency not only on the payer’s side but on the company’s side too and called for a revision of EU transparency regulation.

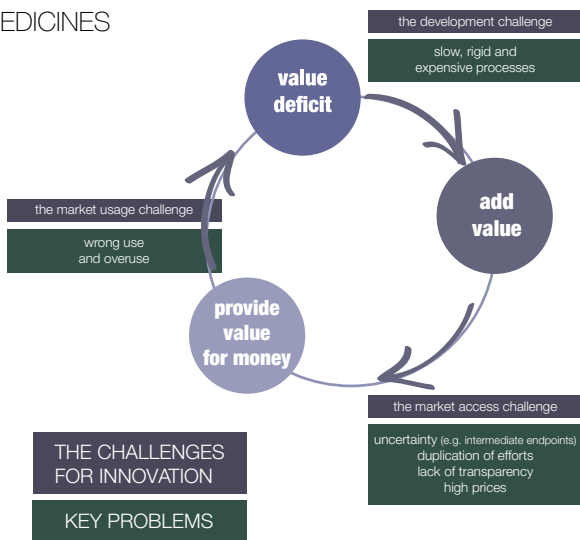
Maria Iglesia, Head of Unit for Healthcare Systems, DG Health and Food Safety (DG SANTE), described the various joint actions between Member States which are ongoing in this field. The objectives of research and development, patient access, the internal market and affordability can sometimes be in competition

but the priority is access for patients to the medicines they need. The problems have been identified but there are no ready-made solutions.

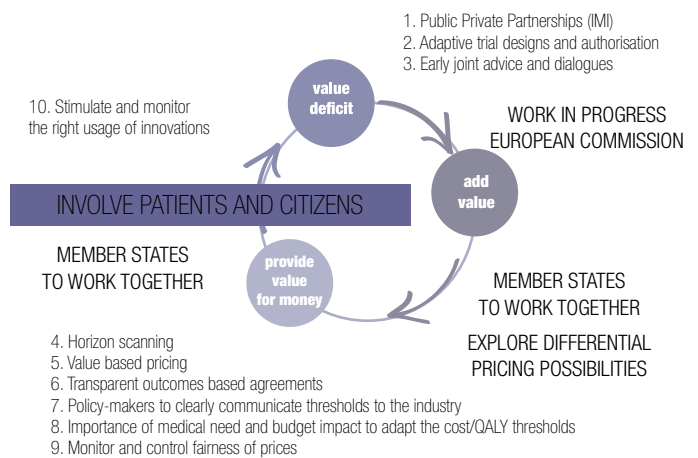
Lieven Annemans, Professor of Health Economics, Ghent University, Belgium, illustrated two ways in which prices may be set: “cost+” price which reflects the cost of research and development (R&D) and “value-based pricing” which is based on the value for money principle. The former approach grants an acceptable mark-up as compensation for the opportunity costs and capital investment of R&D but may provide the wrong incentive particularly in the case of multiple R&D failures and it is difficult to assess the true cost of R&D. The latter approach provides an incentive for better research leading to more value but the profit margin may not be a reasonable proportion of the cost. The need for Member States to work together was strongly highlighted in Annemans’ concluding recommendations.

Susan Spillane, Senior Pharmacist, National Centre for Pharmacoeconomics (NCPE), Ireland, Young Forum Gastein Scholar, highlighted the limitations of some oncology trials which may receive authorisation following, for example, a single arm phase 2 trial reporting surrogate endpoints. Such trial designs pose significant challenges from a HTA point of view. Spillane highlighted the potential for terminology such as “breakthrough” to be misleading, particularly for patients and the public and proposed that greater engagement and communication with the public on these issues should be a priority.

### THE PRICE OF INNOVATIVE MEDICINES



### 10 RECOMMENDATIONS



Source: Lieven Annemans, The price of innovative medicines - Views from a health economist (Power Point Presentation, October 2015)

Pascale Boulet, Independent Consultant in Medicines Law and Policy, was surprised at how little intellectual property was at the centre of the discussion. Patents are temporary monopolies to reward companies for their research efforts. These rights are not granted without obligations; the innovation must be made transparent in order to make the products reproducible. Patents have become ever more complex and companies design their work smartly to extend patents and exclusivity rights. Legislators can take steps to ensure that patents do not hinder access to medicines. Boulet advised that compulsory licensing is not only used in developing countries but also, for example, in the US when patents are misused for market power. She suggested that Europe could potentially go beyond the EU for ERP.

The discussion was closed by Hans Kluge who reminded the audience that the issues at stake are complex and the solutions are not simple. Regulatory and system changes are required but may take time. The challenges however are real and now. Governments have a responsibility to provide medicines for all patients not just for those with high profile diseases. A fair reward is required for industry alongside equal access and sustainable health systems. The WHO will continue to work with member states to ensure equitable and affordable access.

■ Written by Emer Fogarty and Johannes Eisenbarth ■

## FORUM 6

Organised by WHO Regional Office for Europe,  
National Institute for Health Disability Insurance  
(NIHDI), Belgium and Main Association of Austrian  
Social Security Institutions



# Access to high-quality healthcare and innovative treatment

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Patients throughout Europe should be able to rely on accessible healthcare systems and have access to innovative, safe and affordable treatments. This forum explored the added value the European Union can have in this debate.

Vytėnas Andriukaitis, the EU Commissioner for Health and Food Safety, opened the forum by relating the issue of healthcare accessibility to the Commission's focus on effectiveness and resilience of health systems in Europe. Accessibility to high-quality healthcare and innovative treatment is explicitly addressed in the European agenda for health. In supporting Member States to increase access to healthcare, the Commissioner identified three main areas that need attention: workforce, access to safe and effective medicines, and optimal implementation of the cross-border directive.

Accessibility in the eyes of the Commission is to be understood as the capacity of health systems to reach the population. As such, accessibility has many aspects, including pricing and investment issues, healthcare structure, workforce, and waiting times. Within this context, it is the Commissioner's vision that in the future the EU and its Member States are better able to identify access related problems and take appropriate collaborative action.

Regarding workforce, the Commissioner is convinced that a sustainable healthcare system should have a workforce that is able to adjust to technological changes and can cope effectively

with the increasingly complex needs of patients. Currently, there are significant gaps both in numbers and in skills of health professionals. Innovative measures are needed to attract and retain a capable health workforce and considerable investments in training and education systems are required to ensure health professionals can cope with future healthcare needs.

The further aspect in improving access to healthcare and innovative medicines is the issue of pricing. There is a growing interest in increasing access to innovative medicines. Joint negotiations for expensive drugs such as the recent Dutch-Belgium initiative might prove effective. At the same time, patients have high expectations and call for a speed-up of the translation of scientific knowledge to accessible and affordable health. However, patient access not only depends on legislation, but also includes technology assessment, pricing and reimbursement decisions. In this context, there are three other issues involved: transparency, trust and solidarity. We need an open debate between pharmaceutical companies, Member States and insurers on medicine pricing, because secrecy can create mistrust in society. We should know what resources are needed, why they are needed, and how they are used. In that sense, Health Technology Assessment (HTA) tools have proved to be important in improving access to innovative medicines and to inform policies with evidence. In addition, mechanisms such as joint procurement actions can be used to help add more value for patients.

## EU AGENDA FOR ACCESSIBLE HEALTH SYSTEMS

How can EU initiatives improve access to high-quality care for citizens? Can access be facilitated by better workforce planning and increased patient mobility? The subsequent discussion in the session focussed on investigating a EU agenda for accessible health systems.

Andrey Kovatchev set the scene by raising the issue of defining the problem of access to healthcare. Every citizen has the right to equal access to health, as all citizens are potentially patients. Kovatchev pointed out that we are in need of reliable health indicators for Member States that help us to understand the heterogeneity of the problem throughout Europe. To that end, a parliamentary platform has been established to exchange the views of all stakeholders, patient organisations, industry, nurses, doctors, health system providers, and politicians to come to a common understanding of what the EU can do for health in Europe. In addition, a pilot project has started recently which aims to define the indicators that can be used to measure access to healthcare. To find appropriate and effective recommendations for changes, we need to understand the specific problems in the various healthcare settings.

Luís Mendão, Vice-Chair, European AIDS Group, took it from there, and being a living experiment of patients rights and treatment of HIV in Europe, provided the patient perspective to the issue of access to health care and innovative medicines. Mendão is convinced that each stakeholder, each representative, has the commitment as a citizen to find the best possible solutions for our societies. Although the costs of developing new treatments are high, all stakeholders have the good common sense of public health that all in need should be treated. However, due to a shortage of resources, choices need to be made based on perspectives of the care and curability of certain diseases. Subsequently, we in Europe are now in the situation of having a real and a fictional economy in medicine pricing. We have external reference prices, which nobody pays, and the real prices that are negotiated by the payers. There is a large gap between the two and this causes a burden to society. It seems that the system is not working in providing health and access to innovative medicines.



Dorjan Marušič, Andrey Kovatchev and Walter Sermeus

Looking at the broader picture, Walter Sermeus, Professor in Healthcare Management, Centre for Health Services & Nursing Research, Catholic University Leuven, Belgium explained that our health workforce is a crucial element in realising quality health care. We need to invest in the health workforce to keep our system sustainable. Elements defining the quality of health care are related to patient safety, effectiveness, efficiency, equity, timeliness, and patient centredness. When translated to the workforce, it includes the planning of the workforce, qualifications and training, costs, distribution of the workforce, job shortages, and the role of the patient. Patients are not only clients, but are part of the system. Furthermore, evidence shows that the mortality rates of standard surgical procedures are highly related to qualifications and the case-load of the workforce. Therefore, we have to be transparent in what the quality of the various health care services are and what patients can expect. We have to invest in high-level care for which the workforce is a crucial and rather complex aspect in healthcare delivery. One of the lessons that healthcare systems can take home is to provide the right infrastructure to healthcare professionals that enables them to be good professionals.

Being part of the Expert Panel, Dorjan Marušič, Former Minister of Health, Slovenia, explained that accessibility to healthcare is the crucial part of healthcare systems. Looking at history and analysing processes we might learn something and avoid mistakes. As a next step in advancing access to healthcare and cross border collaboration, Marušič is convinced that local problems should be dealt with locally. However, this cannot be done without the support of the global environment to prevent problems from becoming a EU burden. In addition, health should be a main priority and not limited to rhetoric in pre-election time or to humanitarian crises. In determining accessibility, Marušič



argued that it is a matter of prioritisation. As pointed out by the Commissioner, HTA can be used to prioritise and define a basic benefit package for all EU citizens. It is a challenge; it is not an idea; it can be done.

## ACCESS TO INNOVATIVE AND SAFE MEDICINES FOR THE BENEFIT OF PATIENTS

As the Head of Unit for Healthcare Systems, DG SANTE, European Commission, Maria Iglesia opened the second part of the session, which focused on access to innovative and safe medicines for the benefit of patients. Key discussion points posed to the panel and audience were:

*Which patient needs should frame the future medicines market landscape and what is the role of the pharmaceutical industry?*

*What are the benefits of a long-term EU-level cooperation and how can innovative initiatives from Member States' cooperation be successfully applied?*

Iglesia argued that it is necessary to ensure a high level of public health and innovation, in order to afford access to medicines and treatments.

Stanimir Hasurdjiev, Board Member of the European Patients' Forum, explored the use of reliable information on quality of healthcare. Hasurdjiev highlighted the relevance of defining access in the context of high quality care. He stated that health services and treatment have to be available when needed, adequate, accessible, appropriate and affordable. However, data protection and data security play a complex and active role regarding patient access.

Marcel van Raaij, Director, Ministry of Health, Welfare and Sports in the Netherlands, expressed concerns about trends to "orphanation". Questions about the impact of pharmaceutical pricing (e.g. price setting behaviour, rapid increases in prices, increasing budget impact), the uncertainty regarding reimbursement and public investment in innovation all play an important role in access to high-quality healthcare and innovative treatment. Therefore, it is necessary to (further) develop and deepen co-operation and exchange initiatives regarding pharmaceutical pricing between Member States, to debate unintended and unwanted effects of pharmaceuticals legislation, to support early access to new, essential medicines and to debate



Richard Bergström, Vytenis Andriukaitis and John Bowis  
Stanimir Hasurdjiev, Karin Kadenbach and Max Müller

future challenges and directions for EU pharmaceutical policy. Furthermore, there is a need to move from supply to demand driven research and production. Voluntary cooperation of Member States on pricing and reimbursement by sharing information market, volume and prices is necessary.

Hans Kluge's talk, Director of Health Systems and Public Health at the WHO Regional Office for Europe, complemented important aspects of the debate about access to innovative and safe medicines. He noted that key topics are financial protection, better co-operation between stakeholders, collaboration between health systems, a greater use of horizon scanning, centralisation of some aspects concerning HTA activities as well as more citizen involvement. Finally Richard Bergström, Director General, European Federation of Pharmaceutical Industries and Associations (EFPIA) completed the session, talking about issues of pricing and value assessments in different countries.

■ Written by Christiaan Vis and Cornelia Henschke ■

## FORUM 9

Organised by DG for Health and Food Safety  
(DG SANTE), European Commission





# Medicine's Adaptive Pathways to Patients

New paths to personalised medicine: How MAPPs and breakthrough designation will impact patients

This workshop was a timely opportunity for distinguished panelists involved in framing the debate on MAPPs and personalised medicines to address the best tailored pathway for breakthrough innovation 30 months after the launch of MAPPs in Europe. MAPPs requires a thinking shift - this is a new way to look at data through an evidence-based approach.

“Medicines Adaptive Pathways to Patients seek to foster access to beneficial treatments for the right patient groups at the earliest appropriate time in the product life-span in a sustainable fashion.”

Source: <http://adaptsmart.eu/>

## MAPPS, BREAKTHROUGH INNOVATION WITH A FOCUS ON CANCER MEDICINES

What can we do to make things better for patients? Cancer was chosen as an example to illustrate the urgent need for an adapted path for personalised medicines, as investment in cancer research is very high. Everything that is done for cancer will help establish the pathway for other diseases, such as diabetes, Alzheimers etc.

Despite the great advancements in cancer research, some important disparities remain amongst Member States varying from low, middle to high survival rates. Personalised medicines could be part of the solution, targeting demonstrated potential benefit and improving the high survival rate tendency.

## PATIENT-CENTRED APPROACH, CHANGE OF PARADIGM?

“We are in a hurry” said Gordon McVie, Senior Consultant, European Institute of Oncology and EAPM Secretary. We need to provide personalised medicines in an era of patient empowerment. This can only happen by facilitating innovation through regulatory change, public-private partnerships, ownership of data and transparency. It is about the future through public education, preparing required workforce skills and mastering technology to overcome silos.

### ACTION REQUIRED - 3 SETS OF POLICY ACTIONS

LIBERATE THE DATA BUT DO NO HARM	BRING IT NOW	PREPARE THE FUTURE
<ul style="list-style-type: none"> <li>■ collaboration</li> <li>■ sharing</li> <li>■ public-private</li> <li>■ partnerships</li> <li>■ transparency</li> <li>■ privacy</li> <li>■ ownership</li> </ul>	<ul style="list-style-type: none"> <li>■ clinical adoption</li> <li>■ data curation</li> <li>■ veracity</li> <li>■ security</li> <li>■ common standards</li> </ul>	<ul style="list-style-type: none"> <li>■ public education</li> <li>■ workforce skills</li> <li>■ ICT infrastructures for life sciences</li> <li>■ bio-informatics</li> <li>■ analytics</li> <li>■ entrepreneurship</li> </ul>

Source: Gordon McVie, Pathways for personalised medicine - Facilitating innovation through regulatory change (Power Point Presentation, October 2015)



Amy M Miller, Carole M Longson and Chris Hoyle

## ACCESS FOR ALL?

All agreed that MAPPs is designed to foster access to breakthrough innovation. Innovation has a cost and it is about assessing whether this cost is worth the investment. Innovative thinking with regard to financing should be envisaged as those paying are not always those receiving the benefit.

Stanimir Hasurdjiev, Secretary General, Patient Access Partnership, questioned how to make personalised medicine a reality for patients. MAPPs allow faster access to medicines but do we keep the same level of safety on innovations placed on the market? How can we accelerate while being effective?

Carole Longson, Director of the Centre for Health Technology Evaluation, NICE, UK, also commented on safety concerns related to MAPPs, where earlier access with fast-track procedures raise doubt and imply taking a risk. From her perspective, the right balance should be reached between “Identifying promise versus identifying promise that should come at an affordable value.” The introductions of new drugs are a challenge for healthcare system sustainability. Stakeholders should strive for managing this uncertainty while aiming for earlier access for patients. “Achieve a change in thinking from clinical development to access as a pathway into a system, barriers that you need to break down, to have access to the healthcare system in a timely and sustainable way.”

Amy Miller, Executive Vice President, Personalised Medicine Coalition, experienced with the US system, referred to the magic around personalised medicines and the science evolving in that direction. Personalised medicines are developed to deliver the right treatment to the patient. In the US one drug out of every five processed by the FDA is a personalised medicine.

Chris Hoyle, Director, Health Economics & Payer Analytics (Oncology), AstraZeneca, stressed that MAPPs is an opportunity to provide the right treatment to patients with earlier access.

His key point was that early access should not be about lowering the evidence threshold. Timely access to the right treatment for patients is a key component of an effective healthcare system.

## QUESTIONS REMAIN

- Pricing of medicines (value has a price, this has to be taken into account, a question of affordability, the “elephant in the room” - find new ways to make products affordable along with the willingness and capability of governments to pay)
- Affordability is a key concern for the industry
- Liability question: who is held liable if something goes wrong with fast track medicines placed on the market?
- What about the post-gathering of data?

## TAKE HOME MESSAGES

### HOW PERSONALISED MEDICINE IS CHANGING THE APPROACH TO CARE?

- One fifth of new medicines in the US are personalised medicines: health systems need to adapt to accommodate the new science of new drug development.
- MAPPs will provide us with greater alignment and evidence from regulatory through reimbursement and HTA organisations.
- Managing timely access to new medicines will be about managing risk and those risks are very complex. MAPPs is the vehicle to identify them and discovering solutions.
- Concerted action is required across three foundational sets of policy actions.
- Globalise the evidence, localise the decision (taking HTA as an example).
- MAPPs is the perfect example why we need more Europe in many aspects, including the regulatory process, HTA and affordability and fair pricing.

■ Written by Ioannis Natsis and Clara Zachmann ■

## WORKSHOP 4

Organised by AstraZeneca, European Alliance of Personalised Medicine (EAPM), European Federation of Pharmaceutical Industries and Associations (EFPIA) and Vital Transformation



# Equity and solidarity

## Equity and solidarity in EU healthcare systems - facts and myths

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This workshop addressed challenges in equity and solidarity in EU healthcare systems by looking at disparities in cancer care and outcomes in Central and Eastern European countries (CEE). After a brief introduction to the topic, MEP Alojz Peterle, President of MEPs Against Cancer sent a video message in which he highlighted that cancer continues to develop faster than society can respond to it and more emphasis needs to be placed on health promotion and prevention in order to decrease premature mortality and increase quality of life.

Federico Paolo from the Healthcare Systems Unit, DG SANTE, European Commission, highlighted that health system solidarity has been a key focus of the Commission over the last ten years, with growing concern about access. The Directive on Cross-border Access to Healthcare could, if properly implemented, provide options for cancer patients in CEE countries to receive better care



Federico Paolo and Ananda Plate

across their national borders but has yet to become successfully established. The Commission is looking to build centres of excellence with the European Reference Networks to benefit European citizens in building the capacity of local healthcare providers with best practice tools in several domains.

Ananda Plate, Operations Manager of Myeloma Patients Europe (MPE), an umbrella organisation of national patient groups, expressed her concern that advocacy has not effectively worked over the last few years due to its over-reliance on anecdotal rather than scientific evidence. MPE has been working towards shifting this paradigm towards evidence-based advocacy. Whilst huge advances have been made in cancer treatment research, there are still significant gaps in access across Europe. In order to understand why these disparities exist, MPE undertook a gap analysis of cancer care in Europe. Desk research was carried out to define the minimum treatment that a patient should expect to receive, irrespective of their geographic location. They also looked at barriers in access to health systems more generally, of which there are many more in CEE. This research methodology and framework could also be useful to replicate for other disease groups.

Martin Price, Market Access Lead with Janssen-Cilag UK, reminded the audience that cancer is the second leading cause of premature death in Europe. Whilst medicines are not the complete solution to

the problem, they do play a significant role in increasing survival rates, and further investment in the area is needed. However, the high costs associated with developing a new drug, coupled with limited patent life, make it difficult for companies to make a return on their R&D investment. He called for bold new moves in the financing of new drugs, including risk-sharing initiatives. He also advocated for the application of equity-based tier pricing, whereby countries pay the drug price based on their level of GDP rather than the International Reference Pricing (IRP) which is currently commonplace. The IRP, he argues, prevents pharmaceutical companies from giving reduced prices to countries who could benefit from them due to the feared domino effect it would have on profits across other markets. A commentator from the floor criticised these comments, urging pharmaceutical companies to show more transparency in their current pricing strategies before new pricing mechanisms are considered.

Price also argued that the Health Technology Assessment (HTA) structures currently in place are too often concerned with cost containment and restrict access to medicines to certain populations. The concept of cost per QALY was his main qualm with the HTA process, which he believed reduced reimbursement decisions to pure economics rather than being concerned with patient outcomes. He argued that price negotiations in individual markets add additional delays to patients receiving the medicines they need. Again the question of return on investment arose and he argued that if drug development takes an average of ten years to get from bench to bedside, two years spent negotiating prices represent two years of lost revenue to the company which has developed the technology. He was in favour of discussing the introduction of European level HTA, although he aired concern that this could potentially add an extra layer of bureaucracy if national level procedures remained concurrently. Criticism came from the floor, suggesting that pricing was not the main problem but rather that “too many drugs and not enough good ones” were currently on the market and that the pharmaceutical industry should focus on more efficient research rather than trying to get high numbers of new drugs reimbursed.



Martin Price and Maciej Niewada

Finally Maciej Niewada from the Medical University of Warsaw spoke about his recent research undertaken in this area. The percentage of GDP spent on healthcare is much lower in CEE than the rest of Europe and increased spending on health must be encouraged to improve outcomes.

## SECURING HEALTH IN EUROPE

This workshop on the final evening of the EHFG highlighted the polemic that ran through the forum on appropriately balancing priorities and sharing responsibilities to secure health in Europe. The EU must continue to play an active role in influencing national policies and countries must follow the lead shown by the EU in incorporating Health in all Policies at a national level. While governments have a vitally important role to play in securing health in Europe, they cannot be expected to be solely responsible; civil society and industry must contribute. We see from the example of Myeloma Patients Europe that umbrella organisations can be very effective in providing a platform for best practice exchange and policy tools relevant for the local level. Yet there is room for more synergies to be made across disease groups. Cooperation from all stakeholders is needed to balance priorities, share responsibilities and enable more solidarity.

■ Written by Nora Cooke O'Dowde ■

## WORKSHOP 5

Organised by Institute for Eastern Studies  
Foundation in cooperation with Janssen





# Measuring “value”

Scoping the “value of innovation”: starting to measure the unmeasurable

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“Measuring the unmeasurable” for scoping the “value of innovation” was the motto of a lunch workshop jointly organised by the European Cancer League (ECL), the European Health Management Association and Roche. Starting from the position that a broad definition of value must be applied to facilitate universal access to cancer treatments, the organisers’ aim was to assess new models of value for taking into account broad societal considerations, which are transposable and scalable across chronic conditions.

The question at the core of this workshop was which criteria should be taken into account when assessing the value of innovation in healthcare. In order to facilitate a productive discussion amongst workshop participants, the organisers developed a board game, where different definitions of value were presented, and participants had to argue for and against those statements.

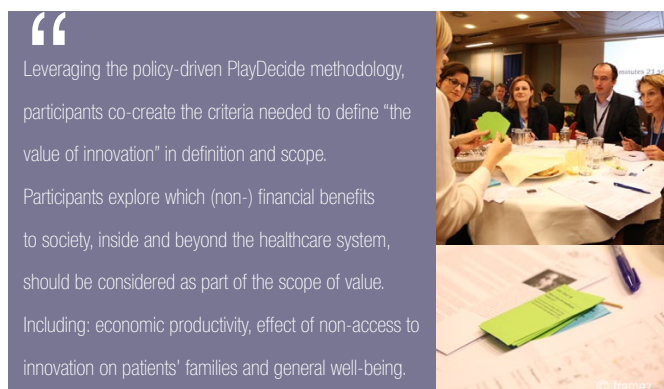
Participants used hypothetical patient scenarios to discuss different perspectives on value and evaluation in healthcare. They discussed which costs, benefits and outcomes should be considered when assessing the value of new and innovative treatments entering the market.

For instance, should economic evaluation take a narrow perspective of healthcare, for example only comparing the Quality Adjusted Life Years (QALYs) gained by the patient and the direct medical cost associated with the innovation. Or should a broader societal perspective be taken, to include for example the impact of innovation on social care, housing, unemployment and workplace productivity, as well as the impact on relatives, informal caregivers or healthcare professionals.

The board game format ensured a lively discussion and allowed participants with various backgrounds to form and defend an opinion.

By the end of this workshop, the organisers fully succeeded in conveying the importance of this question in the context of allocating scarce healthcare resources amongst competing innovations entering national healthcare markets.

However, due to the limited time available, it was not possible to discuss in-depth the practicalities of each perspectives on economic evaluation. Such practicalities include constraints in





terms of data availability, variations in assessment methodology, the potential for setting adverse incentives, and ultimately the need to base allocation decisions in the healthcare sector on comparable information across different interventions, populations, and care contexts.

Beyond raising awareness of the issue, the results of this workshop may therefore not instantly help in forming a new position on how to assess the value of innovation, and which criteria ought to be considered when assessing the cost-effectiveness of new and innovative treatments entering national healthcare markets. However, it is unquestionable that a narrow healthcare perspective often falls short of capturing the “true” value of innovation.

This workshop provided a clear signal to researchers and decision-makers to further develop economic evaluation methodology in order to incorporate, on a more regular basis, different economic perspectives and to compare how changing perspectives may impact on healthcare decision-making.



■ Written by Christian E H Boehler ■

## LUNCH WORKSHOP 2

Organised by European Cancer Leagues (ECL),  
European Health Management Association  
and Roche



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