

Conference report

Health in Europe – Making it fairer

18 March 2014, Brussels





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The conference entitled 'Health in Europe: Making it Fairer' took place on 18 March 2014 at the Charlemagne conference centre in Brussels. The conference aimed at highlighting current issues on fairness in health, access to health and discrimination in health in Europe; exchanging information on policies and good practice to improve the situation; identifying ways forward and what more needs to be done in the future.

The conference built on the high level meeting on HIV and Human rights (May 2013) and the session on discrimination in healthcare in Gastein (October 2013).



Around 400 participants attended the meeting, representing a broad range of civil society organisations, national governments and regional authorities, public health professionals groups and EU and international organisations. Among the main speakers were Tonio Borg, the EU's Commissioner for Health, Viviane Reding, the EU's Commissioner for Justice and Fundamental Rights, Adonis Georgiadis, Greece's Minister of Health, Ingrida Circene, Latvia's Health Minister, MEPs Livia Jaroka, Jean Lambert, Alojz Peterle and Antonyia Parvanova, Michel Roland from Doctors of the World and Robert Johnstone representing the European Patients' Forum. There were three parallel sessions which brought together stakeholder organisations and representatives of national government and EU institutions on chronic disease, vulnerable groups and HIV/AIDS.

Social media

More than 1,350 tweets were posted on #EU4Health - the conference hash tag - with an estimated reach of 80,000 people⁽¹⁾.

(1) https://storify.com/EU_Health/health-in-europe-making-it-fairer-eu4health

First panel of speakers

Paola Testori Coggi, Director General of the European Commission's Directorate General for Health and Consumers, opened the conference by stating that tackling discrimination has been and must remain a fundamental tenet of the EU. She highlighted the common values and principles of the EU's Health Strategy, which are: universality; access to good quality care; equity and solidarity. Other core values are citizen's empowerment and the use of the best evidence for health.

Tonio Borg, the EU's Commissioner for Health, emphasised the EU's commitment to combatting discrimination in all its forms and his personal commitment to the issue. He made a commitment to take the fairness in health issue forward through EU health policies and through support for activities during the Greek and Italian presidencies of the EU.



Ingrida Circene, Spyridon-Adonis Georgiadis, Tonio Borg, Viviane Reding and Paola Testori-Coggi, Director General of DG «Health and Consumers» of the European Commission (from right to left)

He argued for more focus to be put on specific areas where stigma and discrimination are a particular issue, including ethnic minorities, Roma and migrants; people with disabilities, mental disorders, HIV and other chronic conditions; people who suffer discrimination based on sexual orientation, gender and age; and the economically deprived and those hit by financial problems due in particular to unemployment.

Commissioner Borg presented a renewed EU action plan on HIV/AIDS up until 2016. The need for continued political leadership, particularly to combat stigma and discrimination in HIV/AIDS, is at the very centre of this action plan. The plan will provide focus on related issues on access to care and on combatting communicable diseases such as tuberculosis and hepatitis. The overall aim is to reduce new infections, AIDS deaths and cases of discrimination.

He concluded by saying that making health fairer in Europe cannot be achieved by any government or institution acting alone and cannot be achieved overnight. He argued that it requires partnerships and sustained application across society and the commitment of individual people.

Viviane Reding, Vice President of the European Commission, mentioned the EU Charter of Fundamental Rights, which enshrines the right of access to preventive health and the right to benefit from medical treatment under conditions established by EU Member States in their national laws and practices. She pointed out that the right to healthcare cuts across many areas, including gender equality, data protection and Roma integration

and mental health. She highlighted the problem of discrimination against ethnic minorities, including the Roma. She referred to a Fundamental Rights Agency survey that highlighted discrimination against Roma by healthcare workers and noted that all EU Member States have presented national Roma integration strategies in four key areas, one of which is health.

Vice-President Reding mentioned the sensitive nature of processing health data and the need to revise the Data Protection Directive from 1995, which did not harmonise the conditions for the processing of health data.

Adonis Georgiadis, Greece's Minister for Health, gave a keynote speech addressing the issue of inequalities and discrimination. He admitted that Greece is facing a large problem in the form of an influx of undocumented migrants and their access to healthcare. The minister also mentioned that, in an era of austerity, negotiations with the troika (the EU, the European Central Bank and the International Monetary Fund) have been of great importance for Greece. A concrete example of good practice in healthcare in Greece is the recent adoption of its e-prescription policy for medicines. The ministry's aim is to reduce annual pharmaceutical expenditure by three billion euro. Minister Georgiadis concluded that more action to reduce health inequalities among vulnerable populations is required with regard to access to health, especially due to the fact that the unemployment/uninsured rate of people has been increasing recently. This can be reached only if the relevant stakeholders (politicians, scientists and civil society) work together.

Ingrida Circene, Latvia's Minister for Health, said that there needs to be increased emphasis on targeted protection, such as organised cancer screening programmes. She also stressed the importance of integrating equity into local government structures and developing local solutions to tackle patterns of health inequalities. She argued that the local level has a leading role in addressing particular groups of the population whilst the government should retain ultimate responsibility. She also made the case for a multi-sector strategy in which EU Member States need to ensure that health is included in all policy fields.

Second panel of speakers

Livia Jaroka, MEP gave a presentation, by video message, addressing the health situation of the Roma and ethnic minorities. She highlighted problems such as poor living conditions, the life expectancy of the Roma being below the EU average, some settlements being left out of, for example, vaccinations and screenings and discrimination with regard to access to healthcare facilities.

Her recommendations included making the Roma a target group of the initiatives, reducing stigmatisation in the medical system and increasing screening in primary healthcare.

For more recommendations, she referred to the report entitled 'On gender aspects of the European Framework of National Roma Integration Strategies', which was adopted by the European Parliament in December 2013.

Michel Roland, from Doctors of the World introduced the recent work of this international humanitarian organisation on programmes providing access to healthcare for vulnerable groups. He mentioned an example of a good practice on universal access

to healthcare from France where low income people have free access to healthcare. In July 2013, the threshold for access to free coverage was increased. In Sweden, the government gave permission for undocumented migrants to have the same access to healthcare as asylum seekers for care that cannot be postponed. All children in Sweden have access to healthcare regardless of their residential status. He pointed out that, in March 2014, the European Parliament stressed the need to bear in mind the impact of austerity measures on the health sector. Greece is an example of this. He argued that governments should adopt recommendations to make voluntary treatment of infectious diseases available to all as a minimum public health measure. He suggested that all pregnant women should have access to antenatal and postnatal care and children to paediatric care. He also argued that EU Member States should separate health and migration policies and that it should not be an obligation to report people without official papers. Doctors of the World recommend launching initiatives on good practice for healthcare professionals.

Speaking on behalf of the European Patients' Forum, Robert Johnstone pointed to a range of problems relating to access to healthcare. These included patients with HIV facing discriminatory attitudes, indirect gender discrimination, age discrimination, increased waiting times for treatment and a shortage of doctors. He also noted that people with mental health problems are sometimes denied adequate diagnosis and treatment. With regard to ethnicity, he pointed to evidence from the Fundamental Rights Agency that vulnerable groups such as the Roma face huge barriers in facing healthcare in the EU.

Low levels of health literacy are another problem. Health literacy is about having the skills to use information and make the right decisions in everyday life. He argued that the costs of low levels of health literacy can be very high.

He also argued that austerity measures in the EU are widening the disparities in terms of access to healthcare.

These sorts of problems can be overcome by empowering patients and effectively diagnosing medical conditions at an early stage, thus making considerable cost savings. Patient empowerment is about ensuring that the patient's perspective is taken into account. Patients can contribute and advise on ways to spend better and to avoid waste as they see many examples of it. Patients also need access to user-friendly and high quality information for their specific needs.

The European Patients Forum sees a joint action on discrimination as being an important step forward in making health fairer for all. For the EU elections, the European Patients' Forum (EPF) has launched a campaign to promote patients' rights. The elections are an opportunity for candidates to hear the voice of patients and to set priorities for the next legislative period.

Jean Lambert, who is an MEP, suggested that EU programmes dealing with training and attitudes linked to antidiscrimination should be carefully considered. She said that the area of temporary work should be looked at carefully, especially in relation to people who are at particular risk of discrimination (e.g. migrant workers and young workers). For example, they might be cleaning ovens but not be given any training on chemicals or any protective clothing. Strengthening the bodies dealing with antidiscrimination legislation was another of her suggestions.

In terms of access to healthcare, she suggested that particular focus should go on Roma women, the elderly and those isolated in rural areas.



Parallel sessions took place after the plenary, highlighting issues and good practices in promoting equity and combatting discrimination in health, including health promotion, prevention and treatment in three key areas: chronic diseases, HIV/AIDS and disadvantaged groups and persons in vulnerable situations.

Parallel session 1:

“Equity in addressing chronic diseases”

Key speakers at this parallel session were:

Ms Wendy Yared, Director, Association of European Cancer Leagues (ECL),

Ms Susanne Logstrup, Director, European Heart Network, (EHN),

Ms Rebecca Müller, Secretary General of Gamian Europe,

Ms Elena Andradas Aragonés, Deputy Director General for Health Promotion and Epidemiology, Ministry of Health, Social Services and Equality, Spain,

Mr Alojz Peterle, MEP,

Ms Ingrīda Circene, Minister of Health, Latvia

Summary

There is stigma and discrimination against patients both at the individual and systemic level. Health is a key determinant of economic growth and a prime political issue and should therefore be kept high on the political agenda. Ensuring equity for all categories of patients is an issue of social justice. Health as a factor of growth should be actively financed and solutions for its high level should be sought. Early retirement should not be an option to 'solve' the problem of increasing numbers of chronic patients, i.e. of the increasing prevalence of the most important chronic diseases. A lot of the barriers to solving the stigma lie in the health systems themselves and, ultimately, should be resolved adapting them to the new realities. Concerted action is needed with the emphasis on multi-sectoriality and multi-disciplinarity. Prevention is the way to go forward with a whole range of activities: primary care, health interventions, lifestyle education and protection of vulnerable groups. Both the EU and the Member States must consider outcomes of health promotion/disease prevention interventions and favour those, including regulatory approaches, which have an impact on the whole population. Equitable access has to be ensured through different measures: financial protection, empowerment, promotional activities and active protection of certain population groups.



Ingrida Circene

More detailed points:

To what extent is stigma and discrimination really an issue?

Stigma and discrimination against patients with chronic diseases are definitely still an issue as they are perceived both at the individual and at the systemic level. At the level of individual experiences this takes the form of difficulties in retaining certain jobs or returning to the same workplace after treatment. Patients with mental problems are often not considered appropriately when they experience somatic disease and its diagnosis may be delayed. Furthermore, patients with chronic diseases are often excluded from clinical trials. A similar problem has been noted with the elderly and women, which are two important groups that are underrepresented in randomised clinical trials (RCTs). Although their treatment increasingly leads to a definitive cure, cancer patients are often not encouraged to live their previous active life (including going back to their previous job) because there seems to be no interest in the issue. Patients with mental diseases often face discrimination in those cases where they concurrently (and to a large degree inevitably) suffer from somatic diseases.

Why does it exist in spite of the numerous existing initiatives against stigmatisation and discrimination?

Apparently, there are a number of reasons for such a situation. One of them is certainly the lack of understanding of the needs of chronic patients and their need to remain actively involved in life at all ages. This is true regardless of age or their actual condition or the state of development of the disease. There is insufficient support for the issues related to people with chronic conditions and clearly insufficient awareness that such an attitude is a barrier to social development. This is ultimately a question of social justice. Chronic disease does not prevent a person from contributing to society. In the minority of cases and at the terminal stage of these diseases, patients need support to maintain their dignity and to obtain the proper level of relief, both at a physical and emotional level. Overall, a lack of understanding about most of the chronic diseases has deep social roots and leads to a lack of appreciation of the problems that sufferers face in everyday life.

There are a number of relevant challenges, such as:

- Adopting the social determinants of health and health equity approach to improve the way in which risk factors, which are unevenly distributed among the population, are addressed;

- Ensuring equal access to the different population groups and different categories of patients regardless of their particular disease;
- Reducing health inequities in life expectancy, in health and in the use of the different treatment options within and between countries. Shortcomings in the central and eastern parts of the EU are still present due to the decade-long divide within Europe.

What are the obstacles to greater fairness in health?

Obstacles to greater fairness in health lie partly in the origins of a lot of today's key health determinants, which lead to the majority of chronic diseases. This is in particular true at the points where there is interaction concerning the consumption of unhealthy foods, where existing strategies need to be reviewed; including a review of the food industry's efforts and involvement. There is pressure to reduce costs, which often results in a reduction of access to services. But there are more problems ahead concerning lifestyles as the population groups who are most under strain tend to either give up on healthy choices or simply stick to their unhealthy habits as they are often cheaper than healthy habits. There should also be more understanding about the social nature of chronic diseases, including mental diseases. As a result, societies cannot simply ignore or discard some of these problems as 'self-inflicted' but need to act on the crucial determinants that decisively affect the outcomes.

From past experience what needs to be done to make health in Europe fairer?

To make health in Europe fairer, it is essential to provide equal access to services in all cases, regardless of the specific disease, gender, age, ethnic or social status. This is the key issue with regard to the question of inequalities in managing patients with chronic conditions in the European Union.

Whenever feasible, it would be appropriate to launch 'positive discrimination' programmes in favour of the currently underprivileged categories of patients and population groups, regardless of the cause of their discrimination.

What needs to be done to improve the way in which stigma and discrimination is addressed? What would be the most important measures?

- Ensuring equality in terms of access (or, at least, improvement in it), which can be proven in an objective manner (statistics, surveys, etc.);
- Remove any overt or concealed methods of discriminating against patients with chronic conditions/diseases in the legal framework;
- Implementation and operationalisation of the existing approaches and policies already adopted at the EU level;
- Recognising that living with a chronic disease does not mean that sufferers cannot live in their normal working and home environments. Instead, it should provide an opportunity for diversified care, in which patients receive the support, actions and care according to their specific needs, including those arising from their specific life context.



What are the roles of the EU, national governments and stakeholders in achieving greater fairness in health and in combating stigma and discrimination in health?

- The EU should encourage all those policies that can have a multi-level effect and can be of benefit to the widest range of population groups;
- EU action plans and recommendations arising from the very well planned and organised EU joint actions should be implemented and put into action;
- Taking note of the fact that, due to the fact that people are living and working longer, there will be more and more active patients suffering from chronic diseases among us (including those who suffer from a growing number of communicable diseases such as HIV/AIDS and hepatitis), national governments should make every effort to protect and assure continuity of care but also to protect chronic patients at their workplaces;
- Stakeholders need to take every opportunity to work jointly towards achieving a solid level of consensus in order to jointly support patients in enabling them to live independently;
- National governments should closely examine what additional actions they are supposed to undertake, given their specific context and economic capacity;
- It is essential to work across the different directorates of the Commission as well as across the different ministries of the particular government. Most of the determinants have multi-factor origins and solving only those most apparent to health will not solve the many other issues;
- EU Member States should strive towards universal coverage and equal access whilst reducing the financial burden to be borne by the individual.

What other aspects need to be highlighted in relation to the conclusions of the conference if any?

All chronic disease patients and also apparently healthy persons affected by the same determinants as the patients are endangered in their health and also potentially in their productive capacity. As populations grow older and as birth rates decline, active populations (i.e. populations from the beginning to the very end of active productive life) will need to be protected with all efforts directed at delaying the impact on their lives and delaying the ill effects of chronic diseases on their productive capacity. As the active populations are the ones that will keep bearing the biggest burden from demographic changes, they will have to mature and grow old in an environment that does not stigmatise those who

have been less fortunate and have fallen ill already long before their retirement age.

A comprehensive approach which includes health promotion and disease prevention is needed to address chronic disease issues.

Parallel Session 2: “HIV/AIDS”

Key speakers at this parallel session were:

Mr Tonio Borg, *European Commissioner for Health*

Mr Tom Hayes, *HIV Activist, UKpositivelad*

Mr Ton Coenen, *Executive Director, Aids Fonds (NL)*

Ms Evelynne Paradis, *Executive Director, Ilga-Europe*

Ms Maia Rusakova, *Director, Regional NGO Stellit, Russia*

Mr Adonis Georgiadis, *Minister of Health, Greece*

Mr Igor Radziewicz –Winnicki, *Undersecretary of State, Poland*

Mr Bernard Faliu, *Head of HIV Infections, Stis and Hepatitis, Directorate General of Health, Ministry of Social Affairs and Health, France*

Mr Luiz Loures, *Deputy Executive Director, UNAIDS*

Summary

The key populations affected by HIV across Europe continue to be people who inject drugs, men who have sex with men and migrants from countries with high HIV prevalence. HIV incidence continues to rise among some of these populations. Additionally, other infections with shared transmission routes (in particular the hepatitis C virus and syphilis) are accompanying the trends we see in HIV in these populations.

The required comprehensive and rational public health response to react to these trends is hampered in part because of continued stigma and discrimination against these vulnerable groups. Stigmatisation and discrimination against all those infected with HIV remain prominent throughout the continent.

Key measures to improve the way in which stigma and discrimination are addressed are to set targets to improve the situation in the next three and five years overall and within each country, to use standard indicators to measure progress towards these goals and to adjust policy if the trajectory is not satisfactory. If the EU cannot control the spread of HIV (and it has not yet been successful in this respect), how can other regions with less resources and poorer integration of the affected communities be expected to do so?

The EU, governments of Member States and other stakeholders have a shared responsibility to work towards zero transmission and an optimal care goal within the EU.

The consequences of poorly operating public health policy as part of the HIV response can be readily detected and hence should be given high levels of political attention. The cost to society for each infection that occurs is significant (e.g. in the UK the discounted additional cost to the healthcare system for the lifelong HIV care of a person infected at the age of 30 is approximately 250,000 euro) and it is therefore both politically appropriate and cost saving to focus on an effective HIV response, including its preventive components (of note: antiretroviral therapy not only ensures health but also makes the person practically non-infectious and hence is an intervention with *double advantages* to public health).

The public health response to HIV remains diverse and inadequate.

There are adequate monitoring and evaluation procedures to document this. There are also highly evidence-based health policies available now to ensure a comprehensive HIV response. The Commission's action plan on HIV is a good example of this. What is missing is political leadership to ensure that it is comprehensively implemented across the continent.



Tonio Borg and Viviane Reding

More detailed points:

To what extent is stigma and discrimination really an issue?

The key populations affected by HIV across Europe continue to be people who inject drugs, men who have sex with men and migrants from areas with high HIV prevalence. HIV incidence continues to rise among some of these populations. Additionally, other infections with shared transmission routes (in particular the hepatitis C virus and syphilis) are accompanying the trends we see in HIV in these populations. The required comprehensive and rational public health response to react to these trends is hampered in part because of continued stigma and discrimination against these vulnerable groups. The stigma and discrimination that runs counter to a rational public health response varies in type and severity. Also, within the EU, laws exist in, for example Greece, which allow for compulsory HIV testing (although the Greek Minister of Health underlines that they have only been used once and that the current government is aiming to nullify them this year). Several countries do not offer comprehensive healthcare to immigrants.

Why does it exist in spite of the numerous existing initiatives against stigmatisation and discrimination?

The knowledge, tools, infrastructure and public health policy frameworks are available across the continent to counteract the trends described above, but they are not being applied well enough. The European Commission released, in March 2014, an EU action plan running until 2016 that outlines the major initiatives required. This action plan is widely acknowledged as being comprehensive. However, the concern is that ministries of health in EU Member States and countries in Eastern Europe may not be fully implementing the EU action plan. Similar types of action plan have only been implemented in a fragmented way in the past. The reasons for this continued reluctance on the part of EU Member State governments and local/regional public health officials remain poorly documented in the literature but are likely to reflect a mixture of financial instability, low priority given by policymakers to this area relative to other perhaps more popular and hence better vote-generating areas of public health policy and the continuing social exclusion of the key affected populations by large sections of the rest of society.

What are the obstacles to greater fairness in health?

In relation to HIV/AIDS, the obstacles relate to two main areas:

- For those already infected, to promote early diagnose in the course of their infection (a deferral of diagnosis leads to poorer health outcomes and unintended forward transmission), ensure that those diagnosed with HIV are linked to and retained in comprehensive care compliant with World Health Organisation-defined standards for clinical staff training, laboratory evaluations and access to comprehensive treatment for all relevant health issues including HIV itself, other infectious (major issues: hepatitis C virus, HPV, tuberculosis) and non-infectious (cardiovascular, liver, renal, neurological and pulmonary diseases linked with HIV) conditions. Care should be provided in an atmosphere of trust, confidentiality and respect for human rights. The fact is that only 50 to 60% of HIV-infected persons in the EU receive this package of healthcare services and another 20 to 25% remain unaware of their status. Scientific studies demonstrate that something as basic as the ability to provide full control of viral replication after starting a person living with HIV on antiretroviral therapy varies markedly across the continent. The scientific literature demonstrates that there are several “missed opportunities” by the health systems to allow early diagnosis of people living with HIV earlier in the course of the infection than is currently the case. Scientific knowledge exists as to how to organise testing programs and health systems to handle these challenges comprehensively and state-of-the-art technical assistance can be provided by centres of excellence. It is, however, recognised that more research is required to further optimise aspects such as testing strategies, linkage to and retention in care, and finally there is a need to improve science with regard to how to improve care for co-morbid conditions including, in particular, multidrug resistant tuberculosis, viral hepatitis and HPV-related conditions.
- It is estimated that 2.4 million people currently live with HIV in the EU and neighbouring countries in the east. Of these, approximately 1.5 million do not yet receive the effective treatment that could reduce their viral load and hence the level of infectiousness and approximately half of these are not aware of their infection⁽²⁾. As such, those not already infected remain at risk of contracting the infection. Scaling up combination prevention, including treatment as prevention, thus remains a major challenge to ensuring a better HIV response across the continent.

From past experience what needs to be done to make health in Europe fairer?

There is a need for strong political leadership.

It would be necessary to implement all components of the European Commission Action plan.

Build the HIV response based on evidence of good public health policy to reduce transmission, diagnose more people living with HIV earlier in the course of their infection and ensure that they have access to state-of-the-art care and treatment;

(2) Some EU Member States have introduced “test and treat” strategies recommending the initiation of antiretroviral treatment immediately upon diagnosis. The 2013 treatment guidelines of the WHO recommend, however, such early initiation only for a sero-discordant couple.

- If focus is lost on one of these components, a negative impact will soon become apparent. There are many examples of this, including the recent outbreak of HIV among persons who inject drugs in Greece due to cutbacks in harm reduction services – a situation that has now been reversed due to the reinstatement of this infrastructure. In addition, there are consistent reports of shortages of antiretroviral drugs in central Europe. Interruption of antiretroviral therapy may lead to a viral rebound of HIV with resistance that can be transmitted to others. Also, a recent report from Poland observed that around 40% of persons diagnosed with HIV in a community testing facility were never linked to care and treatment.



Mr Adonis Georgiadis

- The legal environment should be conducive to this – laws that lead to criminalisation of people living with HIV, men who have sex with men and women are counterproductive; the exclusion of immigrants from access to some or all healthcare services is not helpful either; particular concerns have been expressed in relation to the practice in some countries of criminalising the purchase of commercial sex services. This comes under national competence but the European Commission aims to consult with the Think Tank on HIV/AIDS to discuss the potentially negative effects of this practice on the prevention of HIV/AIDS and other sexually transmitted diseases.
- The uninhibited access to antiretroviral treatment (but also treatment for the hepatitis C virus and multidrug resistant tuberculosis) is key – the high prices of drugs are a potential barrier in this respect – consider voluntary multi-country procurement of these drugs and consider switching to generic drugs where available.
- Place NGOs and other community organisations at the centre of the response – past experience shows that the involvement of civil society leads to better control whereas exclusion leads to the opposite. Reach out to the communities affected – engage them and ensure that they are placed centrally in the response to HIV.
- Consider consolidation of public health policies between HIV and viral hepatitis – shared transmission routes and hence overlap in those affected (people who inject drugs, men who have sex with men, sex workers and migrants) and comparable technical handling of testing, access to and retention in care (hepatitis C virus is now a curable disease after just eight to 12 weeks of treatment).
- Focus policy on best practice examples with a distinct focus in order to appreciate that there are many examples

of poor practice that will run counter to good intentions and hence should be avoided.

- Continue to ensure that implementation research is productively ongoing in order to further refine the HIV response. Make sure that these efforts are coordinated across borders in networks to ensure that they are complimentary (and not redundant). Past experience informs that there is not one single public health policy that works for all aspects of the HIV response, so diversification is an asset.
- Make sure that surveillance is created that captures key indicators as to whether public health measures are appropriate (e.g. percentage of those diagnosed early on, percentage of those late presenting themselves for care).
- Finally, political leadership also means publicly embracing those that are stigmatised and discriminated against.

Parallel session 3:

“Health of People in Vulnerable Situations”

Key speakers at this parallel session were:

Ms Mary Baker, *President of The European Brain Foundation*

Ms Vappu Taipale, *Former Minister of Health, Former Director General of Stakes, Finland*

Ms Vera Regitz-Zagrosek, *Director Berlin Institute of Gender In Medicine (Gim) Germany*

Mr Anas Salih, *Community Worker, Ex-Irregular Migrant, Belgium*

Ms Mariana Sandu, *The Roma Center For Health Policy – Sastipen, Romania*

Ms Lavinia Lo Curzio, *Director of The Facility Management Unit And Head of Territorial Office for Foreigners - Health Department of The Local Health District (Asp) of Syracuse, Italy*

Ms Antonia Parvanova, *MEP*

Summary

There is a considerable amount of stigma and discrimination faced by vulnerable communities when accessing health or trying to access health. This includes the Roma community, migrant communities, sex workers and transgender persons but also the unemployed, the elderly and children with learning difficulties. Vulnerability can lead to long lasting health problems, losing one’s job, poverty and social exclusion.

Obstacles to making health in Europe fair(er) included fear of accessing health (by vulnerable groups) or fear of providing healthcare (service providers when, for example, faced with a migrant with an irregular status); language barriers and cultural barriers; the vagueness of procedures on health issues; health inequalities and the lack of political will to prioritise health care; and a lack of knowledge about disease prevention and lack of information about rights and procedures for access to health services.

To combat inequality in health, cross-sectoral and multi-governance layers were recommended. Only partnerships between

state authorities, patient and health organisations, international organisations, civil society and health professionals can be efficient in tackling the problems.

Good practices referred to health mediators in the Roma community (Romania) and to doctors who come from an immigrant background providing healthcare to members of their own communities (UK). The importance of strengthening local authorities' capacity to address health needs was also stressed.

More detailed points

To what extent is stigma and discrimination really an issue?

Several speakers in the panel and the audience referred to widespread stigma and discrimination faced by vulnerable communities when accessing health or trying to access health. Persons belonging to minority groups, including the Roma community, migrant communities, sex workers and transgender persons are affected but there were also accounts given of larger groups in society being affected, including the unemployed, the elderly and children with learning difficulties. Such vulnerability can lead to long lasting health problems, losing one's job, poverty and social exclusion. It was recommended that socio-economic determinants serve as indicators of worse health and that preventive health interventions should take such determinants into account.

Why does it exist in spite of the numerous existing initiatives against stigmatisation and discrimination?

Several speakers pointed out that, despite legislation in the area of non-discrimination and in the area of access to health assistance for migrants (e.g. in Sicily, Italy), access to health is not always guaranteed in national legislation, or even if it is, is not available in practice. Even if it is, communication and information on rights is not always available to the most vulnerable in society. In some instances there is a lack of clarity as to the coverage of the right to (access) health, for example if only emergency care is covered or also regular care.

Irregular migrants are often afraid to seek medical help because they do not have valid ID documents or residence papers. Sex workers who live in countries where sex work ('buying sex') is a criminal offence also face barriers in seeking and receiving medical care. NGOs representing transgender persons reported that, in 14 EU Member States, sterilisation is a legal requirement in order to obtain legal gender recognition.

What are the obstacles to greater fairness in health?

Despite the different problems faced by different vulnerable groups, there were remarkable similarities in the obstacles identified.

- Fear of accessing health (by vulnerable groups) or fear of providing healthcare (service providers when, for example, faced with a migrant with an irregular status);
- Language barriers and cultural barriers;
- Vagueness of procedures on health issues;
- Health inequalities and the lack of political will to prioritise health care;
- Systematic inequalities in society, starting in the school system (example given: segregation in schools);
- Among the main barriers to accessing health services are lack of knowledge about disease prevention and lack of information about rights and procedures for access to health services (e.g. only a quarter of Roma are considered to be informed of the factors influencing people's state of health, which shows the acute need for information).

What are the most important measures needed in order to improve the way in which stigma and discrimination is addressed?

- Gender: Basic scientific medical research needs to take into account differences between women and men. Most research today is done in young male mice and the results are then translated to females – or women – without any criticism, without respecting female hormones or the female cycle. The present picture of myocardial infarct, for example symptoms, diagnosis, interventions – is made from men and for men. It is not recognised that women may have different symptoms, require different diagnostics or therapeutics. It was therefore recommended that medicines and treatment need to be adapted to biological differences. It was also recommended that EU-funded research projects in this area should explicitly be reviewed to take into account this gender aspect. Teaching in medicines and textbooks should also be critically reviewed on this point. A positive practice is the EU-funded action *EuGenMed*⁽³⁾ on the implementation of sex and gender in biomedical research and healthcare.
- MEP Parvanova made a strong plea for pilot projects focusing on inequality in health and referred to a European Parliament initiative in this regard. In addition, Fundamental Rights Agency studies on inequality in health (focusing on multiple grounds) were recommended as good practices.
- Some speakers stressed that the focus when discussing fairness in health and vulnerable communities should not

(3) <http://www.eugenmed.eu/>

only be on the rights holders but also on the duty bearers including service providers (health professionals). We need to know more about the obstacles that they face when offering health interventions.

- It is important to keep on taking a rights-based approach in access to health. Charity is not sustainable. Only a rights-based approach can ensure a long lasting impact in terms of improving people's health and making a fairer Europe.



What are the roles of the EU, national governments and stakeholders in achieving greater fairness in health and in combatting stigma and discrimination in health?

Cross-sectoral and multi-governance layers were recommended when combatting inequality in health. Only partnerships between state authorities, patient and health organisations, international organisations, civil society and health professionals can be efficient in tackling the problems.

Good practices referred to health mediators in the Roma community, but, at present, the health mediator's status in Romania is uncertain and will vary depending on the capacity of understanding on the part of local authorities of the role and specificity of the activities carried out by the health mediator.

Another good practice referred to doctors who come from an immigrant background providing healthcare to members of their own communities (UK). The importance of strengthening local authorities' capacity to address health needs was also stressed.

Key Conclusions

The following are highlights of the vast array of subjects covered during the conference:

Reform of health systems

As stated in the WHO Tallinn Charter: health systems for health and wealth⁽⁴⁾, "A health system is the ensemble of all public and private organisations, institutions and resources mandated to improve, maintain or restore health. Health systems encompass both personal and population services as well as activities to influence the policies and actions of other sectors to address the social, environmental and economic determinants of health".

There is a need to reform the health systems in the EU Member States to make them sustainable and more inclusive. Longevity is on the up as is the incidence of chronic diseases (e.g. Alzheimers or diabetes). Eleven EU Member States have received EU country-specific recommendations on health.

Cuts in health expenditure

Budget cuts are having a devastating impact on health promotion and prevention even though there is strong evidence to suggest that investing in health promotion and prevention has a long standing impact on improving people's health and thus reducing treatment costs in the long run.

An assessment of the consequences of cuts in health expenditure is needed for the whole of the EU. We can learn from examples from the past: Finland was in a deep recession in the early 1990s and made cuts. The impact of the crisis for health has been evaluated and negative mental and social consequences of these cuts have been observed on the second generation of people who were at risk then.

Health is a right

As stated in Constitution of the World Health Organisation (WHO)⁽⁵⁾: "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being..." in this sense, health should be guaranteed as a right.

The right to health is not only the right to be healthy; it needs to take into account the social determinants in order to meet the citizens' rights and the highest attainable level of health. It must be stressed that health is crucial for our wellbeing and that our freedom and everything we are capable of depends on our achievements in health.

Health equity

Health equity means that all individuals are able to enjoy their highest health potential regardless of their social position or other circumstances determined by social factors.

From the point of view of public policies, health equity means that resources have to be allocated according to people's needs. It also means equity in health outcomes for all social groups.

Health equity is a value linked to concepts such as human rights and social justice. Amartya Sen, member of the WHO Commission on Social Determinants of Health, pointed out the following: "Health equity cannot be concerned solely

(4) http://www.euro.who.int/_data/assets/pdf_file/0008/88613/E91438.pdf

(5) <http://apps.who.int/gb/bd/pdf/bd47/en/constitution-en.pdf>

with health as an isolated factor. Rather, it must come to grips with the larger issue of fairness and justice in social arrangement, including the economic distribution, paying appropriate attention to the role of health in human life and freedom. It is true that Health Equity is not only about the distribution of health or about the distribution of healthcare, which are more restricted aspects. In fact, Health Equity has an enormous scope and importance.”

Make health equity a cross-cutting, explicit and practical axis of all public health activities and plans, of health services and of all other policies which have an impact on social determinants of health in order to guarantee equitable health opportunities and results for the whole population.

A methodological guide⁽⁶⁾ published by the Spanish Ministry of Health on how to integrate equity into health strategies, programmes and activities has been mentioned as an interesting source of information.

Health in all policies

EU Member States need to ensure that the objective of health equity is included in all policy fields. A multi-sector strategy is what is needed. E.g. finance ministries and governments need to be persuaded that health is not just for the health ministry but should cut across all ministries because some of the issues linked to health inequalities lie outside the health sector. Social determinants of health include areas such as employment and working conditions, education, housing and social policy. It is also very important to integrate equity into local government structures and to develop local solutions to tackle patterns of health inequalities. The local level has a leading role in addressing particular groups of the population. However, government must retain ultimate responsibility.

Health promotion and prevention

EU Member States are spending an average of around 3% of their health budgets on health promotion and prevention of illnesses and 97% on treatment. This 3% of the different budgets spent on prevention needs to be used more effectively. The message needs to be conveyed to governments that it is in their interests to invest in health promotion and prevention that reaches all people regardless of their socio-economic status.

Health promotion and prevention is the way to go forward with a whole range of activities: primary care, health interventions, lifestyle education and protection of vulnerable groups (among the general public too).

The results of health promotion and prevention are to be seen in 20 years or so when most politicians have retired. The momentum here needs to come from the grassroots (e.g. from patients). There is a difficult balance to be reached as prevention will pay dividends in the future but there is a need to pay for treatment now.

There needs to be increased emphasis on targeted protection – e.g. organised cancer screening programmes.

Empowering patient groups and consultation

To be empowered, patients need support from healthcare professionals. Patients need to have a central focus, both in terms of their duties as well as their rights.

The patients' perspective needs to be taken into account as patients can be part of the solution to many of the problems. For example, on the one hand a healthy population need to learn to develop their maximum health potential and, on the other, patients with chronic diseases have to learn to navigate the health system. They can help overcome gaps/problems but are rarely given the chance to do so. Patients can also contribute and advise on ways to spend better and

to avoid waste as they see many examples of it.

Patients have a fundamental right to access user-friendly and high quality information. There is currently a lack of targeted information for specific needs.

More patient focus can help the EU find real solutions to real issues. A system could be devised where people could send in complaints about the system to make sure inequities in health systems are known to all and to help find clear responses within the relevant system.

A recommendation here is to set up a multi-stakeholder partnership group to raise the issue of access to healthcare. This could include patients, healthcare experts, industry etc.

Dealing with stigmas and discrimination

A lot of the barriers to solving the stigma lie in the health systems themselves and, ultimately, should be resolved adapting them to the new realities. Concerted action is needed with the emphasis on multi-sectoriality and multi-disciplinarity. Only partnerships between state authorities, patient and health organisations, international organisations, civil society and health professionals can be efficient in tackling the problems.

When talking about discrimination, stigmatisation and equity in relation to access to prevention, late diagnosis and early testing, the 'men who have sex with men' community is often among the most marginalised and discriminated against in society and yet is disproportionately affected by HIV. There is a need:

- to enhance action on HIV prevention strategies and services for men who have sex with men;
- to provide evidence-based research of the current status of HIV prevention strategies and services for the 'men who have sex with men' population;
- to assess availability, affordability and accessibility of sexual and reproductive health and HIV services for men who have sex with men;
- to check whether 'men who have sex with men' programmes and policies operate from a rights-based approach and whether advocacy, representation and participation in decision-making are possible.

Lesbian and gay organisations have not said much about HIV recently as they are faced with a stigma. It has to be borne in mind that there are still prejudices about various illnesses. This needs to be addressed through more networking.

Stigma index

There is a stigma index for people living with HIV that is used in some countries. It was started by UNAIDS. A stigma index is important in terms of advocacy and monitoring. It makes the issue visible, measurable and quantifiable, it allows cross-country comparisons, and benchmarking. The use of a stigma index for people living with HIV has led to the empowerment of patients as it has helped them to manage their own illnesses.. Something like this could be done for other health conditions.

Access to healthcare

Minimum access to healthcare for all (regardless of their residential status) should be granted by adopting recommendations by Member States. Minimum standards should include making the treatment, at least of infectious diseases, available to all and ensuring that all pregnant women have access to antenatal and postnatal care and ensuring access to all children to paediatric care to make sure that they have the best start in life.

Health systems should guarantee quality and equity and be sensitive to the different needs of the population.

(6) http://www.msssi.gob.es/profesionales/saludPublica/prevPromocion/promocion/desigualdadSalud/jornadaPresent_Guia2012/Methodological_Guide_Equity_SPAs.htm

Healthcare providers play a key role in reaching out to vulnerable groups. Examples of good practice may include doctors delivering services for migrants in their own language or the use of Roma health mediators.

There is also a need for training for healthcare professionals to ensure that the delivery of services is not discriminatory for the patient. This is about medical staff but also the gateways to the health system too. It might be at the point of reception and not necessarily at the point of delivery. Funding could be used for that in the future.

Legislation

The enforcement of antidiscrimination legislation, both at European and national level, needs to be strengthened.

Both the EU and the Member States must consider regulatory approaches that support action on risk factors and that have an impact on the whole population.

Exchanging best practices and avoiding bad practices

Exchanging best practices is very important in various areas as there are lots of differences between countries. One example relates to access to jobs for cancer survivors. Here, it would be useful for countries to share best practices on this and to work out guidelines to protect these people. There is evidence that could point to bad policies. It is important that when there is evidence that something will not work, EU countries should avoid committing resources to that. Metrics to indicate if a policy has been successful are needed. These could cover areas such as health in all policies, health promotion, prevention, policies for reducing health inequities, early diagnosis, ageism, obesity etc.

Indicators

There is a need for indicators covering the subject of the conference. Armed with indicators that should be monitored over time, EU countries can see if they are going in the right direction. Without indicators, it will be very difficult to sustain political momentum.

These indicators should take into account social variables to monitor social determinants of health and health inequities.

Increasing health literacy

Health literacy is about having the skills to use information and make the right decisions in everyday life. Low levels of health literacy and uneven distribution between different socio-economic groups is an important issue. The costs of low levels of health literacy can be very high.

Health and migration

EU Member States should separate health and migration issues – it should not be an obligation to report people without papers. Developing comprehensive policies which address social determinants of health is a key question for improving the health of migrants.

Gender balance

Gender is a social determinant of health and should be taken into account in a cross-cutting way in order to achieve equity. Gender balance should be respected at the level of those holding leading positions and research objectives. Guidelines or modules for guidelines related to different needs for the treatment of women and/or men should be developed.

Health and temporary work

People in temporary work may be people at particular risk of discrimination (e.g. migrant workers and young workers). For example, they might be cleaning ovens but not be given any training on chemicals or any protective clothing.

Follow-up with EU Member States

The key issue is to ensure that issues discussed during the conference will be followed up and will get into mainstream policymaking at regional, national and EU level. The conference could be followed up by reporting to EU Member States in the EPSCO Council. The Commission will discuss this with the Greek presidency of the EU.