



MEETING MINUTES

Event Name: 9th European Patients' Rights Day

Theme: The Challenges of Chronic Diseases and Patients' Rights in the Framework of EU Healthcare Sustainability

Date: 12 May 2015

Conference Organizers: Cittadinanzattiva Onlus-Active Citizenship Network

Hosted: MEP David Borelli (Co-Chair of Europe of Freedom and Direct Democracy Group) and MEP Gianni Pittella (Chair of Group of the Progressive Alliance of Socialists and Democrats)

Venue: European Parliament, Altiero Spinelli Palace, Room A1E2

OPENING KEYNOTE

Mariano Votta, Director of Active Citizenship Network

The conference was opened by Mariano Votta who thanked everyone, especially the two MEPs, Hans Martens and the leaders of the various organizations, for showing their support to the 9th European Patients' Rights Day. The goal of the conference was to increase awareness on the topic and facilitate the exchange of different points of view, identify concrete strategies and actions to strengthen citizens' participation to create efficient, sustainable and equitable European health systems. He gave a brief overview of the lack of sustainability in the health care system and the costs associated with it. He introduced the two sub-topics, the risks associated with not tackling the challenges and the Interest Group. The latter is not only a "watchdog" to the European Commission's activities in the field of patients' rights, but will also promote initiatives with the involvement of civic and patient organizations.

MEP David Borelli, CO-Chair EFDD

MEP Borelli highlights several points on the relationship between the European Union and chronic diseases:

- Debates in the European Union are too focused on topics far from the reality of citizens and that the European Union should re-focus on topics relevant to the daily life of citizens. Therefore, "nothing is more important than health and nothing impacts more than diseases" on the daily life of citizens.
- Even though there have been huge steps in the healthcare system, diseases have not been eliminated rather have been transformed. One of the reasons is due to the ageing



population which has led to new types of diseases. Moreover, the healthcare system still does allow the vulnerable and the poor to access its benefits.

- Medical care is not the only solution: patients should know about their rights and have access to reliable information, especially in being active actors in protecting their rights and in policymaking.
- Prevention, research and innovation are important for healthcare and should not be limited in the hospitals. Organizations dealing with health care are important and should be made valuable as they are a link between society and the medical world.
- There is a need to discuss not only which is the best healthcare but to work in having a minimum standard to access good quality healthcare.
- The economic crisis has led to cuts and restructuring in the healthcare system and it had a huge impact on the citizens. That is why it is important to focus on healthcare, especially on chronic pain, as the main point of debate and to bring it at the European level.
- The role of politicians and policymakers should be to protect the citizens' rights and support these kinds of initiatives.

Based on the importance of institutionalizing the European Patients' Rights Day and the work done over the years by Cittadinanzattiva-Active Citizenship Network, MEP Borelli is in favor and supports the creation of an Interest Group.

MEP Gianni Pittella, Chair of S&D Group

MEP Pittella expressed the importance of the topic by underlining the coming together of two different political groups. He gave a brief but concise speech on the problems and the future of a sustainable health care system:

- The main problems are: it needs to tackle a more ageing population which brings old and new chronic diseases with limited resources and it is too expensive, as 7 hundred billion euros per year are spent on chronic diseases and its 75% of the EU budget.
- The quality of health care systems and the sustainability of socio-economic resources should be a long-term goal.
- Bringing back the EU to its main objective i.e. defending the rights and dignity of citizens, and strengthening the relationship between citizens and EU institutions. Demonstrate to the citizens that the EU really has its citizens at its heart.

MEP Pittella supports both the European Patients' Rights Day and the Interest Group which should be monitoring and bringing innovative ideas for the healthcare system.



OVERVIEW

Martin Seychell, Deputy Director General of DG Sante

Martin Seychell divided his speech in three parts: chronic diseases, patients' rights and sustainability of health systems. For each he gave a brief overview of the difficulties faced and the actions taken by the DG Sante.

Chronic Diseases

- Chronic diseases are an increasing burden in an ageing society, especially for patients suffering from multiple chronic diseases. It represents the main cause of death in Europe and 80% of healthcare costs.
- The role of the European Union can add value and make important contributions to support member states in improving their healthcare systems.
- The DG Sante's approach to chronic diseases are to:
 - recognize that major diseases (cardiovascular, musculoskeletal, respiratory, diabetes) should be addressed in a holistic manner by tackling a number of common risk factors, such as: lack of exercise, obesity, consumption of tobacco and alcohol;
 - create specific action plans for some diseases (cancer, dementia, rare diseases) such as: early diagnoses, secondary prevention and treatment in healthcare as they need to be addressed in a specific manner.
- Tackle the various stages of chronic diseases, especially prevent what can be prevented. Those that cannot be prevented should have an effective management system through patient empowerment. The patient should be the main actor as they are the ones who receive the medical treatment and go through the process.
- The DG Sante participated at the concluding reflection process with the stakeholders and member states on which factors lies the added-value toward a EU election. These factors are: prevention, care, innovation and research. The follow-up of this process was the [Chronic Diseases Summit](#) held in Brussels on April 2014: the key conclusion was a call to reinforce activities in all those areas that can impact the reduction of the burden of chronic diseases.
- The Commission launched [a joint action](#) on ageing and chronic diseases in 2014 with a budget of 10 million euros. In this action:
 - it supports EU member states towards a more efficient prevention and management of chronic diseases;
 - it gives attention to equity and the impact of social determinants on people's access to care;
 - an EU Framework and practical tools need to be created to support member states in their national strategies dealing with general and specific chronic diseases.



Patients' Rights

- Directive of patients' rights and cross border healthcare, a major piece of EU legislation, as it creates for the first time basic sets of patients' rights in the EU law. At the heart of the Directive is the concept of informed patients taking empowered decisions. A [Memo](#) of ten benefits that the EU brings to the patients and a [EU Barometer](#) will be published soon. The latter is on the level of knowledge and information that patients have at their disposal to exercise their rights in cross border care.
- Lack of transparency is not an option: people want high quality and real-time information and want to act on the information and not be passive recipients. Health systems need to accept this as they are resistant to change. Also, information to citizens before they become patients should be reliable and of quality, so that once they become patients requiring care, they can act on it.
- The Commission launched a mapping exercise across the EU on how patients' rights are enforced. The results will be published in October and will be available to all stakeholders for their national policies.

Sustainability of Health Systems

- Innovative solutions should be created to deliver better healthcare.
- The healthcare of tomorrow will be decided by the decisions of healthcare today.
- The following questions should be addressed: are patients available to have access to quality healthcare? Is healthcare really improving? How effective are they? Are our health systems sustainable?
- The Commission proposed an EU agenda to support member states in:
 - strengthening the effectiveness of health systems to improve the health population services;
 - increasing accessibility to everyone;
 - improving the resilience of health systems in adapting to changing environments and tackling limited resources.

He concluded that "health systems are not effective and accessible if it's not doing its job today; health systems that are not resilient are not going to do their job tomorrow".

Mary Harney, former Health Minister and Deputy Prime Minister of Ireland and Chair of the European Steering Group on Sustainable Healthcare (ESG)

Mary Harney opened her speech with pointing out that "there is no perfect healthcare system and everyone is striving to achieve a good healthcare system" and gave various examples:



- In 2012 in the EU, the average age was 83.2 and 1/6 suffered from disability. It lost 2.5% of its GDP (240 billion euros) due to workers taking leave from work prematurely and 10% of the youth not working due to disabilities.
- For example, in 2011 the USA had 30 patients accused of chronic conditions, ½ were not based on evidence and only 11% of interventions were effective.
- In the analysis of the ESG, three basic recommendations for change came up:
 - universal healthcare in the EU;
 - early intervention and prevention, for example:
 - in Spain, for every euro spent on multiple sclerosis, 11 euros were saved (return of investment);
 - Workplace intervention: every euro invested can save 3:1 workers on medical care and 2:1 fewer absentees;
 - empowering patients and informing patients on treatments: doctors should be the guide not the god. The World Health Organization has stated that patients stop taking medicines in accordance to the prescription after 6 months.
- Members states should be encouraged into early intervention and prevention: only 3% of the budget is spent on prevention.
- Health care should move from hospital care to community and primary care. For example, the chronic obstructive pulmonary disease (2nd reason most patients end up in hospital) costs the same as managing 8 years of the same disease in the community.
- In the EU less than 10% of hospital care is provided with mobile technology. Mobile technology can monitor better, is cost-effective and safer.

She concluded that if a European Patients' Rights Day and an Interest Group are organized, patient's rights should be the main focus.

THE ROLE OF DIFFERENT ACTORS IN SUSTAINABLE HEALTHCARE SYSTEMS

MEP Piernicola Pedicini, ENVI Committee member

MEP Pedicini gave a short introduction to sustainability and focused on recommendations towards a better health system.

- Sustainability can be divided in two sectors:
 - Political:
 - values of solidarity are moving towards materialistic values;
 - individualistic systems are more common than equity; in other words, not everyone has access to health care.



- Economical:
 - availability of resources;
 - costs and recession: during the economic growth, health care costs increased more than GDP. Instead during the recession, there has been a reduction on resources and waste. Increased demand for healthcare is due to: increased ageing population, disease prevalence and needs perception. It should be noted that healthcare costs are not correlated to an ageing population but the latter has an impact on the performance of healthcare.
- Recommendations:
 - healthcare costs: should be based on quality (performance) not on quantity (refunds);
 - promote meritocracy: support doctors that manage to prevent and intervene adequately to decrease the costs for the patients;
 - report on safer healthcare in the EU: improving patient safety and fighting antimicrobial resistance;
 - patient-centered approach: politics should not interfere on healthcare professionals' decision on patients' treatment; healthcare should not be affected by austerity and should encourage multidisciplinary approach;
 - patient safety: early warning and ensure proper training for professionals;
 - eHealth: it is a resilient system to treat chronic disease. For example, home care or telemedicine will make healthcare more sustainable;
 - encourage blame-free and anonymous reporting of adverse events;
 - line 34 in the [Report on safer healthcare in Europe: improving patient safety and fighting antimicrobial resistance](#): Recognizes the value of citizens' initiatives, such as the European Charter of Patients' Rights based on the Charter of Fundamental Rights of the European Union, and the European Patients' Rights Day, which has been organized every year on 18 April since 2007; invites the Commission and the Member States to support the European Patients' Rights Day at local, national and EU level.

Maria Iglesia Gomez, Head of Unit D2 Healthcare Systems – DG Sante, European Commission

Maria Iglesia Gomez introduced the agenda for effective accessible and resilient health care for EU patients to tackle challenges in the health systems with limited resources. To improve the health system, member states should be more resilient and focus on outcomes.

- The agenda recommends the following three points:



- Strengthen effectiveness by: improving quality of healthcare and patient experience. There are 3 ingredients to this:
 - performance of health systems: it can be measured with reliable and good data. This measurement is a technical exercise done by the EU Commission, which is working on a common methodology which can be used at the national level. Member States have been asked which priorities they want to measure first and they have replied: firstly measure the quality of healthcare and its outcomes and secondly work in integrated care;
 - patient safety: to measure safety there is too much information but lack of real implementation. Thus, work on existing best practices and with the different actors to implement the best practices and develop instruments, such as financial instruments;
 - capacity to integrate care and cure in health systems: integrated care is not only about integrating primary and secondary care but integrating social budgets with health budgets.
- Increase accessibility:
 - planning of the health force: member states need to have strategies to plan the needs of healthcare professionals, help in continuous health development and retain professionals where mobility is an issue;
 - access to innovative medicines: work with member states and patients on how to access certain medicines and tackle unexpected expenditure;
 - the patients' rights Directive 2011/24: this is about designing the basket of benefits for patients, how treatment is reimbursed and informing patients on the costs and their rights in getting treatment in another member state, as some member states require prior authorization before crossing their borders.
- Improve resilience: it is not only about being sustainable but making the systems able to tackle challenges with limited resources. Some recommendations are to implement:
 - Health Technology Assessment, which should be coordinated at the national level.
 - Health Information System: compare reliable data as it helps in measuring performance.
 - eHealth: an important element that will help the efficiency and design of future health systems.

She concluded that patients are becoming more and more digital and that health system should reflect this change, and increase the effectiveness of outcomes with less resources.



**Roser Vallès Navarro, Director General of Planning and Health Regulation, Ministry of Health,
Government of Catalonia**

A positive case study highlighting how different actors have improved the sustainability of healthcare systems in Catalonia (Spain). The Ministry of Health works under the umbrella of the health plan of Catalonia 2011-2015. It involved citizens, patients, organizations and administrations.

- Catalonia has a qualitative system. The Ministry of Health's task as policy makers is to guarantee the sustainability of the system. They have identified a lot of factors that impact health care systems:
 - living conditions, increasing expenditure and less healthy habits: the government has created the Inter-Ministerial Public Health Plan (PINSAP). It involves 30 new actions, 14 scopes and 2 axis. When designing and assessing public policies it should be taken into account the point of view of patients;
 - increase in life expectancy and in chronic disease prevalence: the government has created the Chronic Illness Care and Prevention Program (PPAC): This program pays closer attention to individuals which gives better results. It has 4 assistance routes with 100% coverage, 3 new assistance routes and a Catalonia expert patient program with more than 4,500 patients managing better their illness;
 - increase in social needs: the government has created the Inter-Ministerial Social Health and Healthcare Services and Interaction Plan (PIAISS): with the participation of the Ministry of Social Welfare and Family and the Ministry of Health, this plan ensures a comprehensive, person-centered care and capable of responding to patients' needs;
 - guarantee equity and equality in health: by giving attention to vulnerable groups, it reduces inequalities in healthcare and guarantees equality to all citizens all over Spain;
 - technological progress: the use of IT tools can achieve a new care model, such as share the clinical history of the patients among the hospitals. This enables participation and co-responsibility, as the patients can access his/her clinical records in a safe way and it allows a faster administrative process;
 - research and innovation: it must impact on the health of patients and improve prevention and diagnosis;
 - 061 CatSalut emergency: citizens can interact with health systems which operates 24 hours and is open 365 days. Moreover, it provides simultaneous translations between patients and health professionals;



- transparency and co-responsibility: the central measures results, assesses and disseminates information obtained in healthcare
- integration of the views of patients and their families: the government has created the Patient Advisory Council of Catalonia (CCPC) which works in all the above projects. Its body is made of patients, relatives and administration. The Government of Catalonia asked CCPC to design & implement a Strategic Plan for the Participation of Patients in the Catalan Public Health System 2013-2016. The main actions and results of CCPC:
 - joint decisions: professionals and patients try the best alternative therapeutic treatments. The patient can voice his/her opinion and choice of treatment and it will be taken into consideration;
 - surveys: to know the needs of the patients not only to diagnose the result, but to take action;
 - annual talks on bioethics: monthly talks in all of Catalonia discussing issues from patients;
 - patient safety course: this course is for the patients, for example, teaching him/her not to take off the id bracelet and the importance of this tool;
 - AVENC: Self-assessment guide for the management of patient organizations;
 - reply to special needs for example: blind patients have their own Braille health card or the Ciud'am card for vulnerable people with special needs.
- For the future, the following factors need to be taken into account: promote active participation of patients in health policies, provide clear information that is comprehensible and useful to citizens, making policies for patients with patients and relations should be based between transparency and trust.

Paolo Giordano, Secretary General European Union of Private Hospitals

Paolo Giordano introduced his organization and showed different examples of private and public health care across the EU.

- The landscape of the EU private health care is different depending on the region: in the north there is a fair competition between providers, in the east there is access to a health care market for private investors and in the south there are late payments by social insurances.
- Examples of private healthcare in the EU:



- Italy: patients can choose between private and public treatments, and both are free as they are covered by the National Social Security Card. The tariffs are imposed by the Government and fixed for several years;
- France: the National Social Security card covers the costs of both public and private treatments and the tariffs are discussed every year;
- Germany: Private hospitals not only deliver a significant share of the hospital services but also contribute to the national economy by paying yearly €100 million of corporate income tax;
- Poland: 60% of all health care is covered by public health insurance and 40% is covered by the patients;
- Spain: Some regions have only public hospitals, other regions have both. Some others have public hospitals managed by private institutions.
- Private healthcare in Agreement with national public health authorities: all agreements and quality controls and tariff prices are decided by the public national health services. Tariffs for public patients in private hospitals are lower than in the public hospitals.
- 60% of all investments are going to HR to employ people, to modernize in medical devices instead 20% are going to taxes. Only the smallest section of the investments are going to the community.
- EU health expenditure and welfare: €950 billion were spent in 2012 on health expenditure. The EU is proud of its system but if it wants to maintain it, it should focus on: efficiency, reducing waste money and stop cutting services for citizens.
- Health expenditure: the EU commission should recommend to the member states that efficiency can be a solution, linear cuts and citizens' salaries should be stopped.
- Prevention: the EU Prevention policies do not arrive directly to the citizens.
- Innovation: invest in technology and new treatments which will increase innovation.
- Medicinal treatment revolution: for example in the 70s a lot of lives have been saved due to the magnetic resonance as it was accessible to patients. Instead now, even though there is a demand for the new melanoma medicine, it's too expensive for the patients, so it isn't used a lot.
- Quality and cross-border patients directive: only 1% of patients are moving abroad as most patients prefer to stay with their family. Other times, the patient can ask to be transferred but that does not mean his/her choice will be taken into consideration. Take for example the UK: even if patients ask to be transferred outside of their country, they are still moved in another part of the UK.
- EU Quality Label: it is needed at the EU level to help patients know the level of quality of the hospitals. It should have a basic criteria and implement the hospital's results.



He concluded that different factors should be improved, such as: better access to healthcare without delay; quality care should be the permanent goal; quality care and information to patients; efficient strategic investments; innovative medicines; modernize health systems and prevention campaigns.

Peter Wiessner, Board member of the European Public Health Alliance (EPHA) and policy Co-Chair of the European AIDS Treatment Group (EATG)

Peter Wiessner talked about the role and responsibilities of civil society organizations (CSOs) in the health care.

- Role of CSOs: it has been growing over the last decades but not in all the countries, for example in Hungary it is shrinking. CSOs are linked with the fundamental rights of people to form associations; ensures transparency, legitimacy of decision-making and policy meets the needs of people.
- CSOs' responsibility is to: represent the people, generate ideas, disseminate information, deliver services and be a critical watchdog.
- Cooperation is needed between the actors and roles in order to secure sustainability. This can be done by: emphasizing prevention and health promotion; increased funding especially in times of crisis (for example in Greece, it shut down some health services, thus hepatitis C and HIV have increased) and improve access to healthcare (the mental attitude of being hostile towards some patients, such as HIV positive patients, should be changed).
- He asks an important question: do we lower our services or exclude some groups of people? The answer: health care should be equal for all.
- Remove inefficiencies in health systems: reduce across the board cuts in healthcare, improve health literacy, mHealth, improve marketing authorization and lower the price of medicines as the price of certain medicines is obscenely high.
- Health in all Policies (HIAP): health should be included in all relevant areas, such as, housing, employment, transport, etc. This can be done with the cooperation between ministries to bring the changes needed.



THE ROLE OF PREVENTION AND INNOVATION IN SUSTAINABLE HEALTHCARE SYSTEMS

Maria Teresa Bressi, Italian Coalition of Associations for Patients suffering Chronic Diseases

Maria Teresa Bressi presented the case study of the Italian health system:

- The health service is public only if it is accessible to citizens but the statistics show that patients have difficulties in accessing due to: work, financial problems, diagnostic delays, rising costs of medicines and lack of integration.
- Italians live longer but worse regarding the physical and psychological aspects.
- Prevention is all talk but no action as Italy spends little on prevention. Patients who want to prevent need to pay out of their own pockets.
- Italy spends less for public health care. Indeed, it is below the EU average. For example, there are lots of medicines which are not covered by the national health service, which leads again, patients paying with their own money.
- The CnAMC recommended the following: more civic participation; decrease private costs for citizens; guarantee accessibility of appropriate and effective therapies; promote and invest in prevention, and ensure that disability is a benefit and not an obstacle.

Celia Marín, Europso Executive Board Member of The European Federation for Psoriasis and Psoriatic Arthritis Associations

Celia Marin brought the case study of psoriasis as a chronic diseases and how it affects the patients.

- Only 2-3% of people are affected from psoriasis and 10% have a genetic predisposition to have the diseases. Psoriasis patients have a stigma. It affects the social and personal relations as it causes: red flakes, itching and pain. It can also lead to other diseases such as: cancer, cardiovascular, depressions or suicide. In the EU, there are 19 million patients affected by psoriasis.
- The costs associated with psoriasis are \$135 billion per year. Those affected with lower psoriasis have lower costs, less medical visits, less use of medicines and higher productivity. Instead for those who suffer from higher psoriasis it is the opposite.
- Innovations should focus on: new treatments, unmet needs, clinical trials participation and better access.



- She asks a powerful question: to treat or to manage the diseases? The answer is both as personalized treatments should be guaranteed as patients will need to manage it for their whole life.

She concluded that healthcare cannot be sustainable without the active participation of patients and that the health systems must meet the patients' needs.

Vincenzo Costigliola, President of the European Medical Association

Vincenzo Costigliola presented the EU health system as one of the best in the world but the quality varies from country to country. This variation depends on economics, politics, working culture and demographic trends.

- Regardless of the variations, all health systems have the same problems: rising costs, flawed incentives, mediocre quality and uninformed patients. Patients want to participate, reduce time and medical errors but sometimes the patient looks only at his/her small part but not at the global view.
- If the EU wants the best efficiency and equity in health, it needs to make sure that the costs are not too high or too low but to reach this optimum point it needs to adapt its resources.
- Biggest challenges: acute and chronic disorders, the current health care outcomes are inadequate and late intervention.
- How do we change it?
 - Patient profile: collect information on the patient since birth so there will be no need to repeat medical tests later in their life.
 - Patient medical record: tailored therapy using new technologies.
- Foreseen changes: predictive medicine and personalized treatment are the medicine of the 21st Century. If the patients gets a checkup before the symptoms appear and is given the right dose at the right time, it gives the patient the maximum chance to survive.

He concluded with a take home message: better quality for less money, adequate investment in creating novel technologies, the transformation of family physicians from individual providers and looking at the individual needs of individual patients into a medical team-members.

Tom Kelley, European Director International Consortium for Health Outcomes Measurement (ICHOM)

Tom Kelley presented the value of costs and outcomes:



- Value based healthcare is best when the patient health outcomes achieved is highest and the costs of delivering those outcomes are lowest.
- Large variations in the cost of care: for example comparing health expenses between India & USA for coronary bypass surgery. USA is vastly more expensive but in India it is cheaper. However, in terms of outcome, there wasn't much difference between them. This tells us that measuring value and doing so at a global scale for outcomes and costs will help to figure which countries achieve the best results at the lowest cost.
- He showed the example of ICHOM in how it is trying to increase the value of outcomes and decrease the costs by bringing the patients opinion in the decision-making process and updating its methodology.

He concluded that transparency is needed in terms of outcomes and costs at the global level, as there is a demand for it.

Carina Schey, Health Economist, University of Groningen

Carina Shey gave a brief introduction on health economics and how it can help to develop an innovative and sustainable health system.

- New drugs or technologies are compared to what is already available to make them cost-effective. For example, Aspirin and Paracetamol are compared in their costs and clinical efficacy, and this determines how one is more effective than the other.
- Instead, for rare diseases and orphan drugs there are no comparisons as each drug is unique to its disease. Hence, new drugs are compared to best practices of standard of care. This means that orphan drugs are assessed to standard drugs and this method is not cost-effective, as new drugs are more expensive to develop and the clinical trials are more complicated. Also, this means waiting and watching without doing nothing. Rare diseases are chronic, very serious and life threatening. There is no time to just watch and wait, especially when there is a new drug being developed.
- Multi-criteria decision analysis approach (MCDAA) is a method to assess the efficacy of a new drug for rare and chronic diseases as traditional methods to assess new drugs cannot be used anymore. This method is fully transparent, not complicated and easy to understand, with the only flaw having a lot of data. Because of its robustness, it can be used to compare drugs within the same therapy, for example, cystic fibrosis where it uses several orphan drugs. It can also be used to resource allocation across therapies.

Carina Shey believes that the MCDAA will gain more momentum, as some pharmaceutical drugs are already starting to use it to assess new drugs.



Elizabeth Kuiper, Director of European Affairs, European Federation of Pharmaceutical Industry

Elizabeth Kuiper focused on four key messages:

- Stronger willingness from member states to explore how increased cooperation across borders can improve access to medicines for patients. For example, Belgium and the Netherlands launched a cooperation to increase access to medicines.
- European collaboration on assessments as a way to reduce duplication and to enable greater clarity, higher methodological standards and improved predictability, along with better and timelier access to medicines. For example, more EU cooperation on HTA as there are different methods in the 28 countries.
- Life Sciences Strategy covers each aspect of a medicine's journey, from the discovery to the development, all the way to how effective access to patients is linked. All these factors should be discussed in a balanced way.
- Proportionate investments in mHealth technology which has a positive impact on adherence, outcomes or efficiency and can ensure that any new healthcare investment is adequately spent. Also, it will help improve patient care and access, patients' rights across border and deliver personalized care.

Nicola Bedlington, Executive Director of European Patient Forum

Nicola Bedlington focused on the last slide of her presentation due to lack of time. Regardless, her concluding remarks were focused and clear on prevention and innovation:

- Prevention is key to sustainability but it's complex and multifaceted.
- Need to invest more on prevention and action across border.
- Prevention is more about equity: there should be no discrimination towards those patients who have not lived in a healthy way.
- Patients are not the problem to be solved but are part of the solutions towards sustainability. They can contribute their experience and know-how needed for better healthcare outcomes. They can also contribute to medicines, technologies, systems and social innovations that work.
- Mapping patient empowerment across the EU is one of the solutions towards sustainability.
- The political climate isn't right to drive patient empowerment yet, but it should put high on their political agenda.



- The last message is that sustainability is a serious issue. There should be a balance between innovation, solidarity and a collaborative approach to create a trusting and enabling environment to move forward.

CONCLUDING REMARKS

Cinzia Pagni, Italian Farmers Confederation

- Prevention and quality were the main points of the conference and it is important to invest on those.
- Supportive of EU supported projects on agriculture, for example, 'Frutta a Scuola' to teach the students the value of fruits as food and to lead a healthier lifestyle.
- Another point is how to promote the quality and certification of foods, not only relying on investments but also on citizens for transparent and legal information on the products.
- Final remark: as a network of citizens working together and sharing information, it is possible to grant patients' rights across the EU.

Antonio Gaudio, Secretary General of Cittadinanzattiva

- No one can change things alone: all the different actors, local, regional, national and EU have come together and spoken towards the same issue.
- Throughout the nine editions of the European Patients' Rights Day, Gaudio has seen that we are going beyond the traditional approaches and accepting new challenges.
- A common idea has emerged from the conference: that the common challenge isn't only to celebrate patient empowerment but to have concrete opportunities to have a common sets of rights throughout the year.
- He underlined that inside the EU parliament a more open minded approach is blooming, for example, MEP Borelli and MEP Pittella contributing together for today's conference.
- The idea of the European Patients' Rights Day and an interest group is an important step towards a more sustainable health care system.

He concluded that "we aren't here to lobby for one day per year to the EU parliament, but to move from declarations to facts. We can win this challenge but not alone".ⁱ

ⁱ Drafted by Renesa Islam r.islam@activecitizenship.net