



**Towards EU elections: a debate on Citizens' expectations with MEP candidates.
Questions and proposals on prevention, innovation and a new health governance for
the European Union.**

Preamble

The associations subscribing this document, together with Active Citizenship Network, strongly believe that:

- A. every human being fulfils several roles at the same time. Among them, the role of citizen and of (potential) patient are included in the same person. For us there is no doubt that citizens will become more active if approached by all stakeholders through this holistic approach;
- B. health¹ is a major common good. Accordingly, we encourage the protection of citizens and patients' rights as well as the promotion of civic activism in the policy-making process with concerns to healthcare issues;
- C. the recognition of patients' rights across the European Union is linked to an increasing demand by the European citizens. The reinforcement of these rights will become effective only thanks to the cooperation and commitment of all relevant stakeholders in each EU country. Thus, it is essential to raise awareness of the importance of patients' rights and of everyone's responsibilities in guaranteeing their respect;
- D. there is a clear added-value to strengthening cooperation among all relevant actors at the EU level, including health authorities, the industry, research and innovation bodies, the healthcare sector and others. However, we first need to guarantee the involvement of the civil society, advocacy groups and patient organizations;
- E. civic participation in healthcare policies should be considered not only as a praiseworthy civic act but also as a strategic source for the safeguard of the public healthcare system. Throughout the years, we have shifted from simply collecting claims to evaluating healthcare providers, promoting a culture of prevention through the empowerment of citizens, etc.;
- F. a well-informed citizen who is aware of his rights is a resource for the society. For this reason, it is fundamental to invest in the empowerment of citizens: to provide correct information on citizens' rights and duties as well as on the risks and opportunities in the health care field; to offer concrete answers to citizens' questions through a more direct communication and information initiatives; to safeguard and monitor the enforcement of norms;
- G. tackling and reducing health disparities is a priority;
- H. we are united by a common language, that of the Sustainable Development Goals (SDGs), which should turn into a shared "culture of doing", starting from Goal 3 "Ensure healthy lives and promote well-being for all at all ages";
- I. to reach the final goal of a European citizenship, we need a common set of rights, in which all citizens can recognize themselves, and a greater civic participation. To contribute to strengthen

¹First published in the British Medical Journal in 2011, we embrace the new definition of health, called "Positive Health". Positive Health as the ability to adapt and self-manage in the face of social, physical, and emotional challenges is a huge step forward to enable and encourage citizens to play an active role in their own health (<https://www.bmj.com/content/343/bmj.d4163.full>).

a European citizenship, we need to put in practice the benefits that the EU brings to European patients².

In occasion of the 13th edition of the European Patients' Rights Day on April 9th, 2019, at the European Parliament, the participating associations will discuss about some of the following topics: prevention (screening/vaccination), patient safety, sustainability, access to innovation and health governance.

For each one of these issues, you can find some figures and remarks below.

Patient safety, healthcare-associated infections and antimicrobial resistance

Healthcare Associated Infections (HAI) are a global concern, further worsened by the growing antibiotic-resistance of the associated microbes. The persistent contamination of the hospital environment contributes to such infections, and the sanitation procedures that have been used so far are not effective in controlling it but may further increase in AMR (antimicrobial resistance).

Recent data released by the European Center for Infectious Diseases (ECDC) have reported that the problem of antibiotic-resistant infections is worsening: in Europe, about 33,000 deaths per year are caused by this kind of infections. For instance, 7,800 people die in Italy every year due to antibiotic-resistant infections contracted during hospitalization, almost twice the number of deaths caused by car accidents. Here, despite the high incidence of this phenomenon, there is a very low level of awareness of the risks associated with HAIs and AMR. Proper prevention practices, together with the adoption of innovative solutions, could significantly curb HAIs, and consequently economically benefit the national health system. As a matter of fact, the costs for treating each single infection range from 5.000 to 9.000 euros.

In order to effectively fight against healthcare associated infections (HAIs) and antimicrobial resistance (AMR), it is necessary to adopt innovative solutions together with a decisive action aiming at raising awareness of this issue among the public. Therefore, it is pivotal to engage groups advocating for patients' rights and to facilitate the creation of a multi-stakeholder dialogue to improve patient safety.

- identify the causes for the discrepancy between the high incidence of AMR/HAIs and their scarce perception;
- promote the uptake of innovative and technological solutions to reduce the incidence of infections in any healthcare setting and antibiotic misuse;
- value the role that suppliers in the healthcare sector can play to improve patient safety;
- ensure a better cooperation and exchange of information across different actors and different levels to monitor progress in controlling infections;
- ensure the continuation of an EU Action Plan with measurable indicators, covering both AMR and HAIs;
- encourage and support Member States to put in place and monitor national targets for the surveillance and reduction of AMR/HAIs through holistic action plans under a "One Health approach". Good practices should be shared between Member States via a dedicated platform;
- create new business models and potentially a new European legislative framework for the improved use of innovative tools to prevent infection and reduce antibiotic misuse;
- raise awareness about AMR/HAIs through educational programmes addressed to healthcare professionals, patients and families;
- encourage the implementation of antibiotic stewardship teams in hospital and healthcare facilities. The EU should clarify the definition of such a team and enable Member States to share best practices in the field.

Prevention & life-course vaccination

²http://europa.eu/rapid/press-release_MEMO-14-341_en.htm

Vaccination is a pillar of public health which, along with nutrition and physical activity, has a key role in strengthening our availability to fight infection and remain healthy and productive throughout life. Communicable diseases, such as measles, hepatitis B and many others, pose major threats to the health of European citizens, although vaccination could efficiently prevent these diseases.

Since 2000, vaccines against measles have prevented almost 15,6 million deaths around the world. Yet, according to the World Health organization (WHO)³, between 2017 and 2018 the cases of measles tripled in Europe, counting 82.596 instances only last year. This represents the highest rate of cases of measles over the last ten years. In 2016, the WHO counted just 5.273 cases. Across Europe, 72 people died of measles in 2018 and 42 in 2017.

We are talking about measles so as to discuss about vaccination more in general and about the necessity to:

- encourage the use of vaccines and the fight against fake news, as the European Council recommendation promoted last December⁴;
- promote a life-course vaccination approach;
- spread citizens' perspectives;
- achieve a “moral suasion” in order to avoid that the topic of vaccination can be politically exploited during the European elections (as well as during those at the national level). The issue of vaccination should be addressed from a scientific rather than a political perspective: less political arguments, political manipulation, and fake news, and more evidence-based information, comprehensible and up-to-date;
- encourage “vaccination vigilance” as well as “professional vigilance” because, as the “State of Vaccine Confidence in the EU 2018”⁵ found out, there is “a correlation between General Practitioners’ (GP) confidence and the confidence among the general public in the survey: countries whose GPs hold higher confidence in vaccines tend to have a larger proportion of the public expressing positive vaccination beliefs”.

Prevention & the key role of screening

Prevention is better than treatment: the EU should add a European dimension to the Member States' efforts on disease prevention. It is a tool to reduce social, economic, environmental, and cultural inequalities in all pathological conditions.

Spending only 3% of our health budgets on prevention, compared to 80% on the treatment of diseases, is simply not enough, also because prevention has been estimated to offer an enormous return on health expenditure⁶.

More than 1.2 million people die prematurely every year in EU countries. This could be avoided through better disease prevention policies and more effective health care interventions⁷.

Screening⁸ represent one type of prevention, through which health services take care of our health. Screening opportunities must be the same for everyone. In fact, health inequalities are one of today's major public health challenges. They signal that health systems are not sufficiently able to effectively deliver preventive and curative services to those populations with the greatest needs.

³<http://www.euro.who.int/en/media-centre/sections/press-releases/2019/measles-in-europe-record-number-of-both-sick-and-immunized>

⁴https://eur-lex.europa.eu/legal-content/GA/TXT/?uri=OJ:JOC_2018_466_R_0001

⁵https://ec.europa.eu/health/sites/health/files/vaccination/docs/2018_vaccine_confidence_en.pdf

⁶ 2015 report of WHO Europe, the OECD and the European Observatory on Health Systems and Policies.

https://ec.europa.eu/health/sites/health/files/state/docs/2017_companion_en.pdf/

<https://www1.oecd.org/health/health-systems/economics-of-public-health-and-health-promotion.htm>

⁷ Health at a Glance: Europe 2018 https://ec.europa.eu/health/sites/health/files/state/docs/2018_healthatglance_rep_en.pdf

⁸ Secondary Prevention—screening to identify diseases in the earliest stages, before the onset of signs and symptoms, through measures such as mammography and regular blood pressure testing. (Wallace RB. Secondary prevention. In: Breslow L, Cengage G, editors Encyclopedia of Public Health [online]. 2006.)

This is a non-optimal use of the increasingly scarce and valuable human and financial resources of health systems.

Today, the cancer survival rate is higher among the most informed people, but such trend could change if there was a greater knowledge of organized screening programs.

Obviously, screening plays a key role in the area of oncology. Over 5 million cancer deaths have been avoided in the EU over the 1989–2019 period. Of these, 440 000 were breast cancer deaths. Breast cancer rates are indeed estimated to fall steadily, with about 35% decline in rates over the last three decades. This is likely due to reduced hormone replacement therapy use, improvements in screening, early diagnosis and treatment.

On the contrary, the growing rate of pancreatic and lung cancer is concerning. The rates of lung cancer will remain quite stable, even if lung cancer trends in women are predicted to increase. On the other hand, the impact of pancreatic cancer will keep rising (more stable among men, increasing among women).

Between 2014 and 2019, cancer mortality has been falling in both sexes: -6% for men and -4% for women. Favourable trends for major neoplasms are predicted to continue, except for pancreatic and lung cancer, whose rates remain unfavourable. This is mainly due to the lack of specific symptoms in the initial phases of the disease and its elevated levels of aggression. Consequently, along with colorectal cancer, pancreatic and lung tumors represent the major challenge for today and for the near future. Overall, in 2019 there will be approximately 1.4 million cancer deaths in the EU, as estimated in the ninth annual report “European Cancer Mortality Predictions for the Year 2019 with Focus on Breast Cancer” published in the journal *Annals of Oncology*⁹. This data is quite stable compared to last year, with some major improvements due to early diagnosis and innovative treatments.

Screening, early diagnosis and treatments are the three main instruments to tackle cancer and, in the case of certain neoplasms, this “weapons system” is gradually succeeding.

- promote investment in prevention is therefore crucial: the unbalanced investments in increasing prevention and reducing social inequalities need to be tackled at the EU level as showed by the differences in cancer screening between people with higher and lower income and education;
- establish EU cancer screening programmes is essential;
- promote EU-wide legislation to protect human health from environmental exposures;
- fight territorial differences on the level of knowledge and the participation of the population is fundamental;
- support a multi-stakeholder participatory process to help remove the obstacles that prevent these programs from being disseminated, effective, known and used.

Sustainability

The sustainability of the European healthcare systems represents a major challenge for governments, healthcare providers and patients. It is necessary to increase awareness of the importance of a shared commitment to reduce waste and inefficiency in healthcare. Although raising funds for health is imperative, having the money will not ensure a universal coverage. The World Health Organization estimated that between 20% and 40% of health spending is wasted because of inefficiency¹⁰. In addition, the Organisation for Economic Co-operation and Development (OECD) estimated that the average life expectancy could increase by about 2 years in Europe, if resources were used more efficiently. Consequently, reducing inefficiencies can lead to substantial gains.

- boost the integration of care, breaking silos between health and social care;
- adopt innovative technologies in healthcare can significantly increase productivity, efficiency,

⁹Supervised by epidemiologist Carlo La Vecchia (Università degli Studi di Milano)

<https://academic.oup.com/annonc/advance-article/doi/10.1093/annonc/mdz051/5382368>

¹⁰ The world health report: health systems financing: the path to universal coverage. - World Health Organization 2010

and it can lead to a better use of resources, greater employees' satisfaction and reduced costs.

Access to innovation

The Council Conclusions on *Innovation for the benefit of patients*¹¹ during the European semester of the Italian Presidency (December 2014) recognised that “innovations in healthcare can contribute to health and well-being of citizens and patients through access to innovative products, services and treatments that have added value with regard to the existing ones and can also lead to more effective ways to organise, manage and monitor work within the health sector as well as to improve the working conditions for healthcare staff”. Nevertheless, in many European countries patients still have to wait long periods of time before the medicines – although already approved by the European Commission on the basis of the EMA/CHMP positive feedback – are actually available.

The European legislation has provided many tools to facilitate the early availability of therapies. However, long national procedures for reimbursement can in many cases delay this availability. In particular, unacceptable disparities in patients' access to innovative medicines – due to different pricing models, authorisation timetables, information accessibility, channels and criteria of distribution, etc. – persist, and they have been made even worse with the adoption of austerity measures and with the reduction of healthcare spending in many Member States since 2009. European and national regulatory authorities and institutions, patient organisations and companies should work together to overcome the increasing number of barriers and inequalities.

In this context, the first steps should concern a clear and shared definition of innovation, as well as current procedures and their transparency for authorisation, pricing and reimbursement in order to bridge the gap caused by the lack both of information and of patient involvement in these processes. Indeed, despite their differences, each National Health System of the EU Member States should guarantee the same rights to patients and people in general.

- promote measures to address inequalities in access to care and health outcomes - within and between countries. Initiatives that further equitable access to and affordability of innovation – without discrimination - should be encouraged by the European Commission with the involvement of all the relevant stakeholders, including national and regional authorities, civic and patient associations, healthcare professionals and the industry;
- Encourage the European institutions to support the reform, sustainability and strengthening of the Member States' health systems by facilitating the sharing and dissemination of best practices, identifying reform priorities, providing financial support for the implementation of reforms, and investing in research to address common challenges;
- guarantee cross-border patients' access to all health services in all Member States, including diagnosis and clinical trials, if this will ensure the best and fastest access to care and innovative treatments;
- ensure the return to work after a severe illness or chronic conditions with adequate support of the employer and of both national and European institutional bodies, through political and financial investment, contributing to an inclusive and fair society;
- prioritize health promotion and disease prevention, patient-centred approaches, digital literacy, health workforce sustainability, patient safety and the respect of patients' rights in general in the EU and in each Member State.

New health governance

The Executive Director of the *European Medicines Agency* (EMA) is appointed also by civic organizations. The Management Board, which is the governing body of the European Agency, is composed of two representatives of European and National Institutions and also of 4 representatives

¹¹<http://register.consilium.europa.eu/doc/srv?l=EN&f=ST%2015838%202014%20INIT>

of the civic society: two representatives from citizen/patient organizations, one from doctor organizations and one from veterinary associations.

- adopt the EMA model within the National Drug Agency in order to ensure patients' involvement in the policy-making and regulatory processes at the national and EU level.

Preliminary questions in occasion of the 13th EPRD:

To open the electoral debate on the future of health at the EU level:

1. Towards the EU elections: which priorities for a healthier Europe?
2. Is Europe focusing enough on health promotion and disease prevention, or do we need to devote more attention and resources to this in the future?
3. How effective is the current approach in Europe in terms of ensuring equitable access to medical innovations specifically and of fostering better health outcomes more generally?
4. In view of the next European elections, what certainties do we have that the above-mentioned issues will be considered by the European Institutions among the priorities for the next years.

Organizations endorsing the document

(As of April 5th, 2019)

- Active Citizenship Network, Italy
- Alliance of Transplanted and Operated ATO "Future For All", Bulgaria
- Associação de Doentes de Dor Crónicas Açores (ADDCA), Portugal
- Association of Doctors for Interdisciplinary Approach for Children with A Disability, Macedonia
- Association of Patients with Cardiovascular Diseases, Bulgaria
- Association of Reproductive Health, Pregnancy and Childcare "Smile", Bulgaria
- Associazione Progetto Endometriosi (APE), Italy
- European Patients Empowerment for Customised Solutions, The Netherlands
- Foro Español de Pacientes, Spain
- Fundacja My Pacjenci (We Patients Foundation), Poland
- Hungarian Patient Forum (Hpf), Hungary
- Institute Innovations, Bulgaria
- Irish Patients' Association
- Lower Austrian Patient and Nursing Advocacy, Austria
- Malta Health Network, Malta
- National Patients' Organization, Malta
- Patients' Organizations With You, Bulgaria
- Universal Patients' Rights Association, Cyprus
- World Federation of Incontinence Patients