



XIII EUROPEAN PATIENTS' RIGHTS DAY 2019

**Delivering patient value throughout the healthcare system.
Focus on Digital Health and Personalized Medicine**

**10th April 2019, 10:00 - 12:30
European Parliament, Brussels**

Opening Remarks and Keynote Presentations

Mariano Votta

Director Active Citizenship Network

Good morning and welcome to the second event of the thirteenth Edition of the European Patients' Rights Day.

Yesterday, here at the European Parliament, we had the opportunity to promote a pre-electoral debate on citizens' expectations with regards to the next European health agenda. The objective of the conference was to ensure that health would be identified as an EU policy priority also in the future, and that patients' rights would be implemented all across the EU.

Today the focus will be on Digital Health and Personalized Medicine. First of all, let me thank the European Institutions, and especially the Member of the European Parliament David Borrelli, for having accepted to host this initiative. This is not the first time he supports our initiatives, showing a particular sensitivity to the demands and concerns of the civil society.

For those who have not participated to this initiative before, I'd like to underline that Active Citizenship Network, the European branch of the Italian NGO



Cittadinanzattiva, has promoted the European Patients' Rights Day since 2007, in order to highlight the importance of the principles contained in the European Charter for Patients' Rights, drafted in 2002 by ACN together with associations from 13 different countries.

From our point of view, today's topic is linked to several rights stated in the European Charter of Patients' Rights: the right to access, to information, to innovation, and to personalized treatment.

We are currently facing a revolution in the health sector. On the one side, a growing demand for healthcare due to the increase in the population's average age and the consequent increase in chronic diseases. On the other side, scientific and technological innovations are subjecting medicine to constant changes. In particular, the digital era is rapidly reshaping the ways in which we perform and receive healthcare.

This revolution is introducing new contents and a new terminology, which has irrupted into our daily lives: digital health, genomic, big data, artificial intelligence, real world evidence, personalized medicine, etc.

With concerns to personalized medicine, today, we are moving away from the idea that the same drug works for everyone, as we are aware that, in order to guarantee the highest efficiency of a treatment, it is essential to take into consideration patients' genetic differences. As a result, new patient-tailored therapeutic strategies are emerging.

Later on, our experts will better explain us what personalized medicine really means and how this is possible also thanks to the digital revolution and the consequent ability to collect enormous quantities of data, which we are able to handle only now.



In the long term, personalized medicine represents a captivating challenge for citizens and patients' associations in which they want to participate, claiming their right to be informed. When patients read articles entitled "How we will defeat cancer through personalized medicine", their expectations become inevitably very high. These are the same expectations that most of the times collide with the everyday flaws of the socio-sanitary system. And this is only the first obstacle that we have to face and try to overcome.

The development of personalized medicine, along with other advances, is leading to a higher number of patients that coexist with cancer as a chronic disease, uncomfortable but under control.

The remarkable progress on personalized treatments opens the door to a wide range of issues. Above all, the fact that several patients are forced to rely on very expensive therapies for decades. Consequently, surviving cancer could remain a luxury for rich people, and national health systems could collapse because of the huge number of patients depending on these therapies. Therefore, lowering costs represents one of the first problems that have to be tackled to bring these therapies in our daily lives a more equitable way in order to avoid disparities among patients.

For those who are committed to the protection of patients' rights, these are other major concerns:

- We need an environment of adequate data infrastructures & digital skills, responsible data sharing for research, ethical safeguarding & appropriate data security: In view of the next European elections, what certainties do we have that



the issue of digital health and personalized medicine will be considered by European Institutions among the priorities for the next years?

- There is no personalised medicine if there is no innovation and there is no innovation without patients. So, how can we merge innovation, treatments' humanization and patient's centrality?
- A database of genomic data, especially if combined with external data on patients, is very delicate: how can we share these data freely without violating patient's privacy?
- Personalized treatments also face numerous structural challenges. Indeed, as science advances, the surrounding infrastructures become obsolete. How and at what cost can we guarantee a rapid alignment of these two?

We believe that patient access to innovation has to be a shared responsibility of all the stakeholders involved in the healthcare sector: for this reason, we have invited top level experts that will help us to know more about digital health and personalized medicine.

I hope that today's meeting can provide an overview of the current and future commitment of the institutions and of the major European players on the topic. Some concrete example will also allow us to share innovative approaches with a positive socio-economic impact on public health. This will be done with a particular attention to disseminate clear and concrete messages with regards to the role of those advocacy associations committed to the protection of patients' rights in the in the framework of digital health and personalized medicine.



If adequately empowered and involved, we are sure that our constituency, which includes several associations across Europe, will join the call for the new European Institutions and EU member states to help improve the regulatory environment so that patients can have early access to personalised medicine, and so that research is boosted.

I thank in advance all the panelists for having accepted our invitation.

Well, I have finished my introduction. Last but not least, let me thank my friend Neil Betteridge for having agreed for the fourth year in a row to chair the conference. His great experience in strategic health issues and his involvement in networks at the national and global level will be beneficial for the discussion of the topics in the agenda.

Thank you once again, I wish you a useful and interesting conference.