



“Patients’ Voice” European Project

Study Visit

Rome, 7-8-9-10 November 2016

Meeting Room: Aula Minerva, Via Suessola 3, C/O Centro Sudi Manieri Copernico -Roma

Welcome and Introduction

Mariano Votta, Director Active Citizenship Network

Good morning everybody and welcome to Rome, considered by many people as one of the most beautiful cities in the world! I hope you had a safe flight as well as a comfortable accommodation.

It's really a pleasure for me to open this study visit, one of the main milestones of the EU project “PATIENTS’ VOICE” about civic activism in the health sector in the northern part of Cyprus.

Please, let me first introduce myself, then my colleagues will present themselves and our organization as well.

My name is Mariano Votta and I am Responsible for European Affairs at the Italian NGO Cittadinanzattiva. I'm also the Director of our European branch called Active Citizenship Network. I have more than 15 year experience in the field of protection of citizens' rights, communication and civic information, stakeholder engagement. For example, the decision to encourage and promote the Member of the European Parliament Interest Group “European Patients' Rights & Cross-Border Healthcare” at the European Parliament during 2015 was actually mine. I took this decision because the recognition of Patients' Rights across the European Union come from an increasing demand from European citizens and the reinforcement of these rights will become effective only with the cooperation and commitment of all the stakeholders in each EU country. Over the years, the EU Commission, as well as civic and patient organizations, have developed several European assessments in order to produce information on the current implementation of patients' rights at EU level. In general, the level of awareness regarding the 14 rights mentioned in the European Charter of Patients' Rights is generally unacceptable. ~~The negative evaluation was also confirmed with the assessment in 18 EU Countries realized in 2013-2014 regarding the “Right to avoid unnecessary suffering and pain”, whose aim was to bring the attention to the condition of patients suffering with chronic diseases and chronic pain.~~ These negative results send a precise signal to the civic society and to the European Institutions about the work that still needs to be done: it is a difficult challenge which needs to be faced as a joint effort. We hope, with this initiative, to cooperate to improve the situation of the Turkish Cypriot community.

Last April, during the launch event of this project - through skype - I suggested how we can do it. In fact, we strongly believe in the role of civic organisations for the empowerment of individual patients and patient organizations.

THE ROLE OF CITIZENS' ORGANISATIONS IN THE EMPOWERMENT PROCESS OF PATIENTS

The key role of citizens' organisations in the empowerment of individual patients and their families is often underestimated. Patients, first of all those with chronic diseases, do not only have to cope with the medical aspects of their condition, but also with the caring, social, relational and psychological aspects of their disease, which often have as much weight as the disease itself on the quality of their lives.

The added-value of citizens' organisations consists of a global approach to patient empowerment, supporting, informing educating and training patients to help them face the many difficulties of their daily lives. This global approach is necessary to make patients strong enough to collaborate with their healthcare professionals on an equal footing, helping them personalize the plan of care, participating actively in the management of their disease, and using health services more effectively.

They play a decisive role in the development of a modern patient-centred health system! Therefore, we believe that the empowerment of patient organizations should be considered as an added value, because they can become real partners in the health policy, sharing with the institutions the responsibility of finding the best balance between the interest of patients and the sustainability of the system. This shall be achieved through the creation of networks and alliances, which allow the identification of common objectives and goals. This includes the development of a global and long-term perspective, which goes beyond the single chronic disease and reflects the general interest of patients.

Patient empowerment does therefore have two different but complementary dimensions:

1. Improvement of a person's capabilities to effectively self-manage his/her disease;
2. Enhancement of patient groups' capacities to participate efficiently in health policies.

In both cases, citizens' organisations – which include self-help groups, associations of patients with a chronic disease, networks and umbrella organisations - play an essential role. And I know they can play a decisive role in this project.

The key themes to reach these goals are trust, collaboration, and communication.

Trust: is an important asset that patient organizations manage. Trust has been lost among many groups, but the public opinion and the Government trust patient organizations. It is crucial for effective allocation of research assets to build trust among all the stakeholders; it starts with open communication and sharing of information.

Collaboration: it is imperative for patient organizations to strategically align themselves and to speak to policy makers with one voice about their goals and objectives. It is also essential for researchers to work with patients from the outset to understand and address their needs.

Communication: Patients must be asked and all their needs must be considered. For this reason we have decided to call this project "PATIENTS' VOICE".

OUR COMMITMENT IN CYPRUS

Well, why we are here today together with you? Because Active Citizenship Network, in partnership with civic societies and patient organizations, is committed to strengthen the protection of patients' rights in Europe. And, at the same time, we strongly believe that empowered patients and their organisations are a resource and not a cost: for this reason we have accepted to cooperate at nation level in Cyprus with the Universal Patients' Rights Association in the framework of the EU "PATIENTS' VOICE" project.

I am so glad to have a so long cooperation with the President Emete Imge, the leader of Universal Patients' Rights Association, that over the years we have invited to attend the European Patients' Rights Day in Bruxelles, to join us in a webinar on cross-border care last March here in Rome, and so on. In particular, we can find the beginnings of this project, as well remembered in her Facebook page by Izlem, in September 2013, when we met together in Istanbul to an International conference on chronic disease. In that occasion, I presented our experience titled "*Fighting chronic disease. The power of partnership: The experience of Cittadinanzattiva*" and at the end Emete and Izlem wanted to take a picture with me and we started to think how we could cooperate together. Since 2014 we have tried to win the call published by EU Commission "EuropeAid Programme" and for sure I would like to congratulate with Universal Patients' Rights Association for the great effort to win it last year.

As co-applicant, in this project we play a consultative role, responsible, among other issues, for this study visit in Italy. Many colleagues have been involved to provide you a very profitable and comfortable stay here in Rome during these 4 days. I want to thank them in advance for their support. Of course we are all at your disposal, so please feel free to contact us for your needs. This is the main and first message I want to share with you.

Talking again about our engagement with Cyprus' associations, even if you probably do not know or nor remember, it's not the first time for my organization to work in Cyprus in partnership with national associations.

We have worked in 2003 with the project "Seminars on Active Citizenship in Cyprus" realizing "Introductory seminars on active citizenship" in the northern and the southern parts of Cyprus.

We have involved Emete in several events as already said and - last but not least - we have promoted this year "Patients' rights have no borders", a European communication campaign on patients' rights in cross-border healthcare in 14 EU Member States. In Cyprus this initiative is coordinated by the patient organization "Cyprus Alliance for Rare Disorders". It is a biannual initiative, you can find a leaflet among the materials we have provided you. We have also some copies in the Cypriot version, so I encourage you to join us for the 2017. My colleague Sonia, that will join us from tomorrow, is the project manager of this initiative and please feel free to ask her more information and details on that.

Comfortable issues

Some practical information according to this study visit. Together with the project manager of the project "PATIENTS' VOICE", we have planned an intensive programme, trying to mix training course here in this building, close to your hotel and our headquarters, with exchange of experiences with several stakeholders and experts: in some cases, as today, they will come here, in other cases we will have to move, it will be an excellent way to experience the traffic in Rome and not just its monuments.

For the selection of the experts, we have of course followed what stated in the project document, so:

- The starting point was the analysis of the main problems you face in your Country.
- Then the heterogeneous categories of stakeholders.
- The third criteria was matching our good relationship with them, their availability, your needs.



To all, we have underlined how useful is to have a pragmatic approach and to share with you in a concrete way how they play an active role in the healthcare sector. From my side, a big thank you in advance to all of them.

The aim is to finish each day by 5 pm., in order to give you enough spare time to relax and enjoy Rome in the evening.

For the whole study visit, the official language is BAD English! In some cases it will be necessary to provide a translation from Italian to English for those panelists who have requested us this kind of support. In these cases, translation is provided by students (Alice, Matteo e Simone) attending a Degree in Linguistic Mediation at Carlo Bo University Institute in Rome and that we thank in advance for their work.

Last but not least, a coffee corner is available as well as restrooms just outside this room.

In closing, I thank you for your attention once again and I'll give the floor to my colleague Daniela can.

Enjoy the day and the study visit!

Mariano Votta