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LIRE
Liga Reumatológica Española

MADRID 2018

AGORA ANNUAL REPORT 2018

7th AGORA Conference

Ilunion Suites Madrid
21-23 September 2018

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Introduction

On September 21-23, 2018 AGORA, the platform of organisations of people with rheumatic diseases in Southern Europe, held the 7th Agora Annual Conference in Madrid, Spain. The aim of the conference entitled “Patients’ involvement in shaping health care” was to facilitate discussions and workshops focusing on the patient involvement in policy decision-making processes, as well as introducing the term Health Technology Assessment (HTA) and exploring the possibilities for patient participation to these processes. Further to this, special attention was given to patient advocacy efforts from an empirical perspective, drawing from the examples of Agora member organisations in Southern and Eastern Europe. Ultimately, one of the main objectives of the conference was to empower and educate patients.

The conference was intended for delegates from Agora member organisations.

Agora General Assembly briefing

Prior to the official start of the Conference, Agora hosted the Annual General Assembly, intended only for Agora members. During the assembly, the delegates discussed Agora’s annual report for 2017 as well as the financial report for the year 2017.

New Agora members

The Agora family was extended by one new member after the General Assembly ratified the membership of the Romanian organisation APAA.

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First Day of the Conference

Opening

Victoria Romero Pazos (Agora Vice President and LIRE President) opened the official part of the conference, while presenting the work of LIRE and its associate regional associations throughout Spain. The various innovative campaigns organised by LIRE on a national and regional level across Spain were truly inspiring for the delegates and proved to be a great resource for new ideas.

Keynote Presentation|

“Engaging patients, healthcare professionals and society in improving healthcare for people with RMDs”

Souzi Makri, ENFA President, CYPLAR Vice President, Agora Past Chair, elaborated on the term and practice of patient advocacy, through the scope of national strategies and efforts. The importance of utilising one’s network appeared to be vital in crashing barriers and overcoming challenges patient organisations face when attempting to influence policy-making processes. Organisations such as EULAR, EUPATI, EPF and EMA can be great allies, as they offer national organisations advice, as well as access to trainings, educational material and diverse tools to empower their advocacy efforts and push strategic items in the agendas of policy makers. Drawing from the previous examples of Agora and ENFA, Souzi Makri concluded that patients as advocates can change the health environment always equipped with the right education and training.

Workshops’ Results|

Workshops A & B| “Patient Advocacy 101: A case study from LIRE & Liga Reumatológica Galega, Spain” & “Patient Advocacy 101: A case study from CYPLAR, Cyprus”

Victoria Romero Pazos (LIRE) along with Catherine van Riel (LRG) facilitated Workshop A, while Souzi Makri (CYPLAR) and Chryso Yiasoumi-Kyriakou (CYPLAR) facilitated Workshop B, under the umbrella topic of patient advocacy technics and methods. Both workshops aimed at providing advice and strategies from the hands-on experience of the LIRE, LRG and CYPLAR initiatives in Spain and Cyprus.

The case study from Spain involved the presentation of the advocacy initiatives organised by LIRE on a national level, as well as a case where the collaboration between the national and regional organisations was the best and most efficient option. Based on the examples, the group in Workshop A brainstormed and came up with a structured step-by-step strategy to help patient organisations prepare for a strategic meeting with policy makers and other stakeholders. Three stages were clearly defined in the strategy:

(a) Steps towards preparing for a meeting: Having a clear topic and pitching it to the key stakeholder is crucial, however the way in which the topic/demand

is presented can make the difference. Therefore, before even entering a discussion with stakeholders, a focused planning and research needs to take place. Lastly, a good communication and media strategy is also necessary and useful especially for the next stages.

(b) How to (re)act during the meeting: During the meeting, it is important for the advocate to be brief, clear and repetitive and utilise her/his strengths. Keeping an eye for detail is vital as this can lead to recognising signals and information from the discussion. Lastly, to ensure that actions will follow, the advocate should set concrete deadlines and secure the contact details of other key people surrounding the policy maker.

(c) Following up after the meeting has to take place: Right after the meeting, it is efficient to send an email outlining the agreements made and the set deadlines to the policy maker. It is recommended to keep the communication active with reminders in case there is no reaction. Moreover, employing social media in smart ways can also contribute to pushing the pitched topic in the policy makers' agenda, however with caution to the regulations.

Along the same lines, Workshop B showcased some of the most efficient strategies and initiatives the patients in Cyprus employed to push important topics on the governments and policy makers' agendas. The lessons from Cyprus highlighted the importance of establishing a committee to discuss topics for patients' rights and create a national strategy for RMDs. During the open discussion, the participants defined the key methods of patient advocacy, such as building strategic alliances, writing and submitting position papers for specific topics, pursuing face-to-face meetings with policy makers, creating a sustainable network of contacts, employing social media, and creating an action plan. Lastly, as suggested also in Workshop A, perseverance and continuous follow-ups are vital to the success of any initiative.

Workshop C| “Patient organisations setting their priorities to improve access to treatment and decision-making”

Workshops C and D focused on case studies and common practices of Agora member organisations under the umbrella subject of policy and decision-making.

Workshop C was facilitated by Fabiola Martinez (Lliga Reumatològica Catalana), who presented LRC's work in the region of Catalonia and outlined the strategy used aiming towards ensuring the presence of patients in the decision-making processes, both on a regional and national level. The facilitator and participants elaborated on the usefulness of both expert patients and patient advocates, roles which despite their many differences, can support and empower patients in being partners in the decision-making processes. An educated patient is an active patient and to this extent an expert patient. Even though not all patients can be patient advocates, there is a need for both roles to exist. Concluding, Fabiola Martinez stressed that the role of patient organisations is of crucial importance as they function as the compass for patients to receive accurate information on RMDs policies and treatments and

thus provide them with a platform to use their expert knowledge of being patients to reinforce or lead patient efforts in influencing policy change for the benefit of the patient community.

Workshop D| “Influencing policy decisions in healthcare: a team effort”

Oftentimes, the notion of team work aiming at influencing policy decisions may sound impossible, especially considering the difficulties encountered in combining the agendas of the different stakeholders in healthcare. Jenny de la Torre (Rheumatology Nurse Specialist), Fran Carreira (LIRE patient) and Dr. Rosario García de Vicuña (University Hospital de la Princesa) facilitated Workshop D to showcase the multidisciplinary teamwork taking place in Spain towards developing a strategy on RMDs for the National Healthcare System of Spain, considering the complicated structure of the Spanish healthcare system. The facilitators led three different group discussions with the participants to brainstorm on methods and ways to engage the patient organisations, the physicians and HCPs, as well as policy makers in working together. As a result, all the group discussions led to the realisation that patients are in the centre of the discussions as they are the glue that brings all the stakeholders together. Nevertheless, patients must first recognise their strength and the gravity of their opinion and claim their seat in the discussion table. Patient organisations have a central role in activating the team effort by:

- (a) empowering patients and providing them with a platform to be more visible;
- (b) engaging physicians and HCPs into combining their clinical and practical experiences with the patients’ personal experiences and helping them set priorities;
- (c) making policy makers and politicians feel empathetic about RMDs patients and present a “sexier” image for RMDs.

Eventually, any policy changes can only be achieved based on mutual agreements with all stakeholders, that will sometimes require the strategic prioritisation of topics, however without patients compromising their rights.

Second Day of the Conference

Keynote Presentation|

“Patients’ involvement in HTA”

Prof. Kostas Athanasakis, a Research Fellow at the National School of Public Health (Athens) and Visiting Lecturer at the Open University of Cyprus introduced the term Health Technology Assessment (HTA) and laid its historical background from a health economic perspective in Europe. Evidently, HTA is the major reform in the regulatory field of patient access in medical technology of the last decades, which can also be a challenge in many aspects. Prof. Athanasakis continued with stressing the importance of patient involvement in the HTA processes. In fact, patients can and must have a distinct role in the HTA process, especially since they promote the transparency and accountability of the process and can help enrich the elements of value that matter from a societal perspective. Despite the value patients can add to the process, the challenge of participating to a highly demanding process is intimidating and poses a barrier. A solution to this problem lies within creating capacity through educated and better informed patients, which will eventually lead to better informed decisions.

Panel Discussion|

“Empowering patients to get involved with HTA”

Following the keynote presentation, Dr. Loreto Carmona (Rheumatologist) moderated a panel discussion on HTA from four different perspectives. Prof. Kostas Athanasakis represented the health economist perspective, Jenny De la Torre the public sector perspective, Katerina Koutsoyianni the patient perspective and finally Dr. Carmona the private sector perspective. The panel had a constructive discussion which led to the following realisations:

- (a) As it appears, especially in Southern and Eastern European countries, patients are not involved in HTA processes. Despite the various efforts taking place to convince authorities and regulators to include patients in the decision-making processes so they can provide empirical data that will contribute to HTA, patient involvement is not a reality in many countries. Nevertheless, patients should not be demotivated and regardless of the fact of not being officially included or invited to contribute, they can still provide input by means of submitting statements on an evidence based manner. In this way, patients will appear as equal partners.
- (b) Patients are intimidated by the term HTA as they see it as a complicated procedure that requires specialised knowledge. Despite the complexity of the process, patients are capable of being involved and they should be present. It is important to realise that no one else knows how it is to live with RMDs, therefore the patient input is valuable.
- (c) Patient organisations have a key role in empowering patients by means of providing access to trainings, such as the programmes offered by EUPATI, EULAR and the London School of Economics, but also through organising tailored trainings using their patient experts. Additionally, patients can start by learning the steps involved in the HTA process to gain a better understanding and keep in mind that even the professional stakeholders

involved do not necessarily know everything about HTA. Overall, patient organisations have a key role in educating and training patients and in helping them build the confidence to request partaking in the decision-making.

- (d) There are various discussions around the use of “soft data¹” against “hard data”, due to the difficulties involved in measuring it and assessing the outcome measurements. Therefore, there is a need to find new methods to assess the outcome measurements of soft data in order to change the prevailing negative perspective. Patients can ask the help of NGOs, Universities, Research Agencies and Research Designers and think along to explore ways in which patient experience and unmeasurable data can be used.
- (e) In general, there is an effort to include patients in earlier stages of the HTA process (not only at the last comparative stage). This is an opportunity the patient community should take into account and try to use towards establishing a more permanent role in the process. In achieving this, patients should define specific actions in which they can contribute.

Workshops’ Results|

Workshops E & F| “Outcomes of the panel discussion”

Following the panel discussion, the delegates were assigned into different groups to elaborate on the outcomes of the panel discussion, setting them into the context and realities of the Agora member countries and their specific needs. Based on the evidence provided by the participants:

- (a) HTA committees are established with patient representatives invited but not included in Malta, Germany, Romania (only invited to 1 workshop);
- (b) HTA committees are (being established) and a procedure to include patients is being developed, however patients are not included yet in Portugal, Spain, Bulgaria, Cyprus, Turkey, Italy, Croatia, Greece;
- (c) HTA committees are established, however patients are not invited nor included in Israel
- (d) Neither of the Agora member countries are invited and fully included in the HTA processes.

Furthermore, the participants agreed that there is a need for Agora to provide help to the national and regional member organisations to support and educate patients to promote their participation to HTA processes. There is a clear need to provide educational material in lay language about the terminology used and the different stages of the HTA process; the duties and rights of patients; training and expertise building (including the awarding of certificates); access to (statistical) data about the epidemiology of RMDs; training on data collection, measurement and analysis; creating partnerships with (inter)national NGOs; help with bringing the knowledge back to each country and translating it into actions.

¹ Cambridge English Dictionary defines soft data as "information about things that are difficult to measure such as people's opinions or feelings"

All participants agreed that soft data are important and should be taken into account. Even though it is a challenge to measure soft data in HTA processes, there are different measurement scales, which can be used, as for example (AQ5D). It is however important to engage academia and other expert researchers in the areas of Social Sciences and Health Economy in this process.

Lastly, all the participants agreed that EMA is an important ally as it is currently working towards establishing a centralised HTA process in Europe. Agora as a platform can facilitate a relationship with EMA in such a way that will allow patients to participate in the different trainings and initiatives organise, as for example contributing to position papers and partaking in the various task force committees established by EMA. There is an important link with EU organisations that should not be neglected.

Gala Dinner

Café Gijón| Madrid

After the official closing of the 7th Annual Agora Conference, all participants had the opportunity to socialise and relax during the Gala dinner. During the dinner, both Agora Secretariat members Elena Tsigki and Evangelos Georgakoudis announced the end of their journey with Agora to pursue other professional opportunities. The Agora Board took the opportunity to thank both of them for their great work and support throughout their time working for Agora.

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Special Thanks

Host Country|

Agora thanks LIRE for their wonderful work in helping organise the 7th Agora Conference in Madrid. A special thank you to Victoria Romero Pazos, Fran Carreira and all the amazing LIRE members for their help during the preparations of the conference.

Agora Chair|

A special thanks also goes to Eva Kritza, for her tireless work as the Chair of Agora. Eva was not able to attend the conference due to health issues, however her amazing work and leadership allowed Agora to host another great conference. The Agora Board is grateful to Eva for her contribution.

Partners|

Agora is grateful to all its partners Roche, AMGEN, Pfizer, Grünenthal, MSD and Novartis for their support and faith in Agora. Without their support the preparations for the conference would not have been possible. Their invaluable support has helped the Agora Conference attain the high standard that it has today.





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