



SIP

Societal Impact of Pain

2017

Structured Cooperation
between Health Care
Systems tackling the
societal impact of pain!

***“Cooperation: Added
value or burden?”***

Souzi Makri
President of ENFA



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Overview of this presentation

- Agora's presentation and aims
- The value of cooperation for Agora
- Benefits of cooperation
- Burdens on cooperation
- Key elements for a successful cooperation
- Cooperation with other Stakeholders:
 - Regulators
 - Pharmaceutical Industry
 - Physicians
- Conclusions



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AGORA:

Working together!

Agora is an umbrella platform representing **19 patient organizations** of people with Rheumatic and Musculoskeletal Diseases (RMDs) from **15 countries** of Southern Europe, with more than **20.000 registered members**





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Aims of AGORA

- ❖ Provide to all of its members with a **stronger voice** at national and European level
- ❖ Working towards creating **better conditions** for people with RMDs
- ❖ Encourage and assist in the foundation and development towards **user-led organizations** of people with rheumatic and musculoskeletal diseases in Southern Europe
- ❖ Promote **supportive attitudes** towards rheumatic and musculoskeletal diseases and enable patients to live independent and participate fully in society



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The value of cooperation for Agora

➤ **Cooperation** is the most essential element at the core of Agora's operation

Through cooperation Agora aims to:

- Establish and promote a common agenda for health and advocacy for people with RMDs in Southern Europe
- Support and safeguard the rights of people with RMDs
- Represent the interests of the entire RMD community at European and national level
- Foster innovation and excellence in education and research with the aim of improved treatment and patient care
- Encourage and undertake research projects related to RMDs and disseminate their results

❑ **Main idea: Cooperation must be delivered in the context of improving quality of care and treatment as well as of promoting the wellbeing and quality of daily patients' life**



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Benefits of Cooperation

- Wider sharing of knowledge, experience, good practices and information -capacity to replicate success stories
- **Stronger and united voice** - effective representation with more power to influence through common goals and interests
- Better use of existing recourses **and easier access to funding sources**
- More integrated approach to patients needs
- Better co-ordination of organizations' activities
- **Mutual support** among organizations
- Increased participation leads to **increased patients awareness** - the message can be transmitted wider



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Key burdens on Cooperation

- Lack of information and experience among the involved partners
- Competition among the partners
- Lack of consistency and clarity on roles and responsibilities
- Resistance to change on something new and improved



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Key elements for a successful Cooperation

- Determination of **clear and agreed mutual benefits and cooperation advantages**
- **Focus on the main aim** of the cooperation
- **Experience on management, leadership and vision**
- **Careful planning and written agreements**
- **Mutual recognition** of cooperation's benefits and commitment to cooperation's purpose
- Ensure that **all necessary safeguards** are in place to protect the collaboration
- **Discuss challenges on potential conflicts of interest in cooperation with all parties**

Example of Cooperation among Organizations

BAB survey (Biologics and Biosimilars)

- **Carried out (2016)** : In cooperation with **EFCCA** (European Federation of Crohn's and Ulcerative Colitis Associations)
- **Involved:** Patients affected by **Rheumatoid Arthritis**
- **Main aim:** Assess patients' knowledge about biosimilars and biologics and to find out to what extent patients are aware of the issues related to these innovative treatment options



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Example of Cooperation among Organizations

- **EUPATI** is a **public private partnership** within the Innovative Medicines Initiative Joint Undertaking, launched in February 2012.
- It is a **patient-led project** coordinated by the European Patients' Forum, with EGAN (Patients Network For medical research and Health) EURORDIS and EATG (European Aids Treatment Group) in key roles including a consortium of patients' organisations, academia, NGOs and industry – 33 organisations
- The **aim** is “**to build competencies & expert capacity among patients and the health-interested public**”



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Cooperation with other Stakeholders

Regulators

Why is it needed?

- Ensure that patients' voices and needs are listened and taken into account in the development of policies
- Enable the regulator to have a clear view and overall perspective on the real-life experiences of diseases and their management
- Facilitate patients' organisations understanding of the competences and role of the regulator
- Contribute to more efficient and targeted communication thus improving awareness of obstacles and problems faced by patients

Cooperation must be based on fundamental principles like transparency, independence and integrity, accountability, appropriate interaction, effective communication and continuous improvement



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Example of Cooperation among Organizations and Regulators

ENFA (European Network of Fibromyalgia Associations) initiated the written declaration 69/2008 on fibromyalgia to the European Parliament

Adopted on 13 January 2009: Call on the Commission and Council to develop a Community strategy for recognition of this condition as an illness, increased awareness of the problem, better access to diagnosis and treatment and research and data collection with regard to the illness



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Cooperation with other Stakeholders

Pharmaceutical industry

Why is it needed?

- Raise awareness for certain diseases by improving diagnostic possibilities and preventive measures, knowing patients' prospects and needs
- Understand diseases and ensure that patients receive the best medical treatment available
- Improve the information provided to patients
- Support medical innovation

□ Cooperation between patient organizations and pharmaceutical companies can and should be based on equal partnership and transparency



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Cooperation with other Stakeholders

Physicians

Why is it needed?

Patients aspect: Take better care of themselves, have better understanding of their condition and treatments and monitor their health by themselves

Physicians aspect: Improve their diagnosis and treatment suggestions while treatments are more effective due to increased patient input

❑ The more doctors and patients work together, the more patients will feel that they are a part of their care

❑ Patients have their areas of expertise too – they know themselves and what is wrong with them



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Conclusions

- It is necessary to **establish closer cooperation among all stakeholders**
- ❑ **Experience shows** that the involvement of patients' organisations has resulted in **increased transparency, trust and mutual respect between them and other stakeholders**
- ❑ **Bringing patients' industry's, physicians' and regulators', viewpoints together ensures that interaction is understood, respected and trusted by all stakeholders as well as external parties and the public at large**



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Disclosure Statement of conflict of interest in the context of the subject of this presentation

Within the past 12 months, I or my spouse/partner have had following financial interest/arrangement(s) or affiliation(s)

- **Support for travel**
- **Honoraria for lectures**
- **Honoraria for advisory board activities**
- **Participation in clinical trials**
- **Research funding**
- **Financial shares and options**
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