avoiding more dimensions in the graph than in the data. Visualisation in Tables is further discussed in my recent article that is freely downloadable.⁴

This year's course will extend introductory material available via YouTube clips on the ARD website (ard.com)! Direct link: https://www.youtube.com/playlist?list=PLXU14EQbU_V9JpmoAKsaCC0VjZbxzAN

Note that you can also sign up for a **special lecture**,

"Theory of poster design and presentation" followed by a **poster tour** after the session, devoted to poster design!

Session Title: EULAR Projects – Challenging Projects in Education and Training

Date/Time: Saturday 16.06.2018 08:30–10:00

Room: Room: E106/E107

Followed by Poster Tour, sign up required!

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Disclosure of Interest: None declared

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THURSDAY, 14 JUNE 2018

Challenges of patient organisations' in the 21 st century

SP0081 PATIENT ORGANISATIONS' CHALLENGES IN A WORLD THAT IS GETTING OLDER – LESS – MORE COLOURFUL

W. Koesters. *Independent, Bergheim, Germany*

We have to see the demographic facts. The most important fact continues to be the birth rate, that is, how many children are born in a country. Because only when children are born, they can start their vocational training or go to college 16 to 18 years later and will be available as qualified workers a few years later. Only those people can in turn have children and bring them up in a way that is sustainable. Only those can become a member of a patient organisation, can be engaged voluntarily.

When you look at the 28 countries in the EU, you will notice that on the one hand the average birth rate is 1.55 (2013) while on the other hand there are still significant differences even within Europe. To keep a population stable, we need 2.08 children per woman aged 15 to 49 years.

The consequences are evident: in almost all European countries the population will shrink without further immigration from abroad or no longer grow on its own. In almost all countries more people will die than be born. This will also have repercussions on the ageing of society and naturally on the demand for products and services too, but also on the potential labour force. This will have consequences for patient organisations too.

At the same time the needs will change because in all countries people continue to get older and live longer. In their old age they will therefore require services for a longer period of time than previous generations: health, nursing care, culture, leisure, housing, support and assistance, travel.

The economy, all companies and professions, the public health, the organisation of daily life will have to face profound changes with long-term effects as well as the associated challenges.

This also against the background of medical doctors becoming older and scarcer as well.

Disclosure of Interest: None declared

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SP0082 HOW A USER-LED ORGANISATION FOR RMDs ENABLES CITIZEN PARTICIPATION IN PORTUGAL

E.F. Mateus. *Liga Portuguesa Contra As Doenças Reumáticas, Lisbon, Portugal*

One of the first challenges faced by patients' organisations may be to become a user-led organisation. In Portugal, for instance, there is still a strong culture of paternalistic relationship between doctors and patients, which can be a barrier when it comes to recognising leadership skills in a patient. This means that

achieving a user-led model within the organisation depends on a) at least one person (patient or carer) feeling able to come forward and assume the leadership, b) this person's ability to gather more peers for the governing bodies, and c) that this team is accepted by the members of the organisation who are used to the paternalistic model. The important role of PARE and EULAR in providing tools and opportunities for developing skills for the empowerment of patients in advocacy, lobbying and as research partners, will be addressed in this lecture, since it can contribute to overcome some of the identified barriers.

Another challenge may be that the desirable concept of patients' organisations as user-led organisations should be duly recognised, for their acknowledgement as stakeholders in the decision-making processes, representing the people affected by those processes. In Portugal, although the National Health Plan for 2012–2016 and its extension to 2020 considers citizenship-based strategies, the predicted involvement of patients/citizens and their representatives, as a key strategic axis to maximise health gains, had been limited to a couple initiatives without significant patient or public. Several patient and citizen organisations have been advocating for increased and meaningful involvement in health decision-making. In 2015, a working group was established with representatives from 13 patient organisations (including the Portuguese League Against Rheumatic Diseases – LPCDR), one consumer organisation and a research centre. The main objective was to develop a Charter for Public Involvement in Health that could be widely accepted and recognised by health stakeholders. However, the group also felt the need to define a consensus on Eligibility Criteria for the Representation of People with or without Disease in Health Decision-Making in Portugal. The final version of the Charter was discussed with political and health stakeholders in a Forum held at the Portuguese parliament that count about 150 participants. The document will now be presented for a legislative procedure in Portugal and it has been accepted in the public consultation on information to be considered during the preparation of the draft guidelines on the effective implementation of the right to participate in public affairs by the Office of the United Nations High Commissioner for Human Rights (OHCHR). This lecture will also focus on lobbying with several tools, from EULAR EU Affairs, Stene competition, PARE conferences and engagement programme, to patients' organisations networks, as a process for a user-led organisation to be acknowledged as such.

The final challenge to be addressed will be the need to empower the citizens' involvement, through education, training and networking for patient advocacy, patients' involvement on health policy decision-making processes and on research. Several empowerment tools to help applying the «users'» arguments and getting involved in multiple areas, to improve access to care, social protection, sustainability, citizens' rights and patients' quality of life will be presented.

This lecture aims to address some strategies, sharing the Portuguese League Against Rheumatic Diseases (LPCDR) experience on engaging the «users'», changing mindsets and tackling the citizen participation of people with Rheumatic and Musculoskeletal Diseases (RMDs) in Portugal.

Disclosure of Interest: None declared

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SP0083 GAPS IN PATIENT TREATMENT – WHAT PATIENT ORGANISATIONS CAN DO?

K. Koutsogianni, on behalf of the Arthritis Foundation of Crete. *The Arthritis Foundation of Crete, Heraklion, Crete, Greece*

Background: Access to healthcare is a basic human right and one of the fundamental principles of European health systems, together with safety, quality, and equity. Unfortunately due to economic crisis and the cuts in healthcare budgets in many countries, inequalities in healthcare have been made worse. Furthermore the healthcare systems are facing increasing demands due to demographic change and the fact that the number of patients with chronic diseases is growing.

Objectives: To identify the inequalities in healthcare system and the degree to which the standards of care are affected.

To outline patients organisations challenges in such a demanding environment and their efforts to overcome the gaps in patients' healthcare.

Methods: Describe the gaps in patients' access to health care and the degree of their satisfaction from the offered health care services as reflected by the relative EPF survey conducted in 2016 among patients in European countries.

In these challenging conditions, patient organisations should help to fill the gaps and suggest specific solutions by raising awareness about the problems of the patients and the consequences of inadequate healthcare. At the same time they should develop collaborations with the scientific and academic community as well as with other patients' organisations.

Conclusion: Patients with chronic and long term conditions have valuable experience as a result of their interaction with the healthcare system and can identify important gaps and propose solutions in order to improve access to healthcare.

Disclosure of Interest: None declared

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