

FRIDAY, 16 JUNE 2017

PARE abstract session**OP0276-PARE MORE PARTICIPATION, BETTER HEALTH – PROMOTING PUBLIC INVOLVEMENT IN HEALTH**

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Background: In Portugal, the National Health Plan for 2012–2016 (1) and its extension to 2020 (2) consider citizenship-based strategies, including the involvement of patients/citizens and their representatives, as a key strategic axis to maximize health gains. However, actual policy initiatives and concrete actions have been limited to a couple initiatives without significant patient or public involvement. On the other side, several patient and citizen organizations (3–6) have been advocating for increased and meaningful involvement in health decision-making.

Objectives: To develop a Charter for Public Involvement in Health that is widely accepted and recognized by health stakeholders.

Methods: A working group was established with representatives from 13 patient organizations, 1 consumer organization and a research centre. A participatory action research methodology was used. The draft Charter was circulated for review and signature amongst more than 200 non-for-profit health-related organizations and over 50 key individuals publicly renowned for their work in health or public participation. The final version of the Charter was discussed with political and health stakeholders in a Forum held at the Portuguese parliament.

Results: A Charter for Public Involvement in Health, including the principles, scope, guidelines and means of participation was developed. In January 2017, 30 individuals (former and current political decision-makers, health care professionals, researchers and patients) and more than 82 non-for-profit health-related organizations (the majority being Portuguese disease-specific patient organizations) had signed the Charter. The conclusions of the Forum show that the Charter was recognized as a very important initiative to promote public involvement in health in Portugal. Challenges and barriers to further advancing patient and public engagement were also identified (e.g. political will, recognitions of patients as partners, patient empowerment, capacity-building, etc.). The Charter and the Forum were covered in the media and follow-up initiatives with health care professionals and hospital administrators are ongoing.

Conclusions: A patient-led Charter, developed by patient and consumer representatives, in collaboration with academia, and the public discussion with other health care stakeholders have proven successful to put public participation in the political and health care agenda.

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OP0277-PARE INITIAL INFORMATION PACKAGE FOR CHILDREN DIAGNOSED WITH JIA

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Background: Both parents of children with JIA and rheumatology nurses have informed FRA from time to time that there is a need for an initial information package. There was a demand for information that catered to children's needs and provided support for them and their closest relatives at the stage when the diagnosis is shared with the family.

Objectives: The aim of the project was to make an information package for children aged 0 to 12. A child with JIA needed to be provided with information that took into consideration the child's age and developmental stage so that any fears that the child might have as a result of him or her learning of the disease were allayed. Not only information is provided through the information package; the content can also be used to encourage discussions between a parent and a child. We also wanted to include items that give pleasure, such as a stuffed toy in the form of a bunny. A further aim was to increase awareness of FRA among

families with children so that as many as possible would find the services offered by FRA and its local member associations.

Methods: The first stage of the project involved conducting a survey in order to find out what the package should contain. The survey was directed to parents to children with JIA, rheumatology nurses and rheumatologists. The content of the information package:

1) An initial information binder with the following information: about JIA, food, physical activities & play, sitting & writing, eyes & dental care. There is also a separate section directed to parents. 2) A so-called gym tail and easy-to-do gymnastic instructions. 3) Bunny 4) Coloured pencils and a pen thickener. 5) A picture book about visiting a rheumatology clinic for the child. 6) Brochures: e.g. information about JIA for the closest relatives of a child diagnosed with JIA and health care professionals, information about FRA for families with children. 7) Gymnastics bag The second stage involved planning the content and the look of the material. The information package and its content needed to be positive and functional – the package as a whole had to be suitable for children. The pictures and text for the picture book were also produced in cooperation with the healthcare professionals. Multiple channels were used to spread the information that the package had been completed, e.g. social media, the FRA website and emails to the target group. In addition, the rheumatology care units were given instructions and informed of what to expect.

Results: The packages were very well received. We have received positive feedback from both rheumatology clinics and families with children suffering from JIA.



Conclusions: There was a real need for the information packages, and the information that they provide help both the families and the healthcare staff. When a child suffers from an illness, it affects the whole family, and hence it is crucial that comprehensive – and comprehensible – information and support are available so that everyday life runs smoothly and is meaningful, and so that a child with an illness does not feel like he or she is a burden to the family but considers him- or herself an equal member of the family.

References:

- [1] We have received positive feedback from both rheumatology professionals and the families of children with JIA.

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OP0278-PARE THE FRENCH PATIENT'S ASSOCIATION (AFLAR: FRENCH LEAGUE AGAINST RHEUMATISM) HAS GENERATED THE FRENCH NATIONAL ALLIANCE AGAINST OSTEOARTHRITIS AND THE FIRST GENERAL CONVENTION OF OSTEOARTHRITIS IN FRANCE: A CAMPAIGN TO CREATE A NATIONAL LOBBYING TOOL TO IMPROVE THE MANAGEMENT OF OSTEOARTHRITIS

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Background: OA suffers from a lack of interest and not considered serious

enough by Health authorities taking into account the burden of the disease. AFLAR has fostered dynamics by creating a structure called the National Alliance against OA, includes national experts, patients and health professionals (HP). A initiative of this group has been to organize the first General Convention for OA. **Objectives:** Its main challenge was to provide a list of actions that could potentially change the face of the disease and improve the visibility of OA along with the needs and demands from French patients. **Methods:** 10 regional roundtables (with HP, patients and health institutions, around five topics) has been launched with discussions and debates and enabled the production of patient-related proposals in order to improve their care and information. **Results:** 79 proposals have been selected and submitted to an online vote in order to be prioritized. Among the 5 topics addressed by the regional roundtables, cross-cutting issues were identified and 9 fields of action emerged. The final proposals were synthesized in a White Paper document and presented to the national Senate assembly. After it was broadcast to the health and public authorities in a prospect of lobbying. see in the image.

Table of the first 21 proposals from the OA French white Paper for the improvement of his management

	Proposal (keywords + listing number)	% of votes	Average /10
1	Positioning osteoarthritis as a chronic and functional disabling disease (1.1)	50,1%	9,02
2	Promote retention in employment for OA patient (3.1)	48%	8,97
3	Involve supplemental health insurances in the healthcare of OA (3.6)	46,4%	8,88
4	Develop research programs to improve the management and treatment of OA pain (4.1)	46,3%	8,91
5	Promote recognition of disability (1.2)	45,7%	8,83
6	Inform health professionals about the total social coverage of the disease through the national health insurance / ALD 31 or ALD 32 in France (3.7)	45,5%	8,88
7	Promote an early diagnosis of OA (2.1)	45%	8,68
8	Promote the training of health professionals in the field of prevention and management of osteoarthritis (2.7)	44,8%	8,86
9	Promote the training of general practitioners on OA non-pharmacological management (2.16)	44,6%	8,77
10	Monitor the medico-economic impact of the stoppage of one part of the OA healthcare repayment in France (3.8)	44,5%	8,80
11	Promote the OA healthcare after surgery by physiotherapists (2.17)	43,4%	8,68
12	Raise awareness of occupational medicine on OA management (1.3)	43,3%	8,71
13	Promote access to physiotherapist for OA healthcare (2.18)	42,2%	8,57
14	Improve the refund of chirocopy care for OA patient (3.9)	42%	8,69
15	Create a national registry of prostheses (2.8)	42%	8,69
16	Find additional means of refunding for OA healthcare (3.10)	41,3%	8,64
17	Develop research programs to improve the management and treatment of OA with non pharmacological pathway (4.2)	41,2%	8,78
18	Favour the creation of conditions of contract for the accommodation of the OA patients(3.2)	40,9%	8,62
19	Promote Patient Therapeutic Education for OA (FTE) (3.16)	40,6%	8,65
20	Favour the practice of adapted physical activity (2.19)	40,6%	8,48
21	Create and generalise an "no pain kit" (2.20)	40%	8,51

Conclusions: Although the impact of this initiative is not yet measurable, we think that it should improve the awareness of the decision-makers on the burden of the disease and provide concrete ideas to governmental and non-governmental policy makers in order to improve the quality of life of OA patients. **Acknowledgements:** L. Euler-Ziegler F. Blanchet F. Beroud CE Bouvier D.Romain Bertholon, SANOIA,SNMR,CFMR. With support of Genévrier, Pierre Fabre, Expanscience Rottapharm Meda laboratory, SOFMER, CONMK & AFLAR **Disclosure of Interest:** None declared **DOI:** 10.1136/annrheumdis-2017-eular.1464

OP0279-PARE NRAS KNOW YOUR DAS APP SELF ASSESSMENT TOOL EMPOWERING PATIENTS

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Background: NRAS has worked with Roche/Chugai for many years on the Know Your DAS resources. As the DAS28 is the most utilised disease measuring tool available and is used in many countries as part of the access criteria **Objectives:** In 2015 the charity was approached about developing an app for mobile phone and tablet use to encourage DAS patient self-assessment. As well as developing the app we worked with the pharmaceutical company to develop printed updated booklets for both patients and health professionals with the addition of information on DAS self-assessment contained within. With increasing pressures on rheumatology clinic time and the emphasis on improving patient education and empowerment this additional NRAS resource is timely and much in demand. **Methods:** The Know Your Das app was designed with clear step by step guides and how to video clips to demonstrate how to use the app and show how patients should examine their own joints. NRAS hosted two user testing focus group meetings and after the launch of version one real time use was analysed. In Jan 2017 version two was released with improvements to the usability and additions including sections on adherence and stock management to aid with prescription refills. The information entered is held securely by the individual but the DAS results can be printed off or emailed to their clinicians as appropriate. It is not envisaged that the patients' self-assessment should entirely replace the clinicians' DAS measurements but that it will facilitate a better dialogue at clinic appointments as it will give a clearer picture of how the disease has been active or not in the intervening time between appointments. **Results:** As of January 2017, 2217 people have downloaded the Know your DAS app and much interest has been shown by users from outside the UK who would like to be able to use the app. Clinicians are keen to utilise the app with their patients

Conclusions: Further research needs to be carried out to compare patients adherence, engagement with their clinicians and ownership of their disease management as a direct result of using the Know Your DAS app. **Acknowledgements:** Roche/Chugai Pharmaceuticals for their funding and development of this resource **Disclosure of Interest:** C. Jacklin Grant/research support from: Roche/Chugai Pharmaceuticals, S. Arora: None declared **DOI:** 10.1136/annrheumdis-2017-eular.1931

OP0280-PARE PATIENT PANELS ON ACCESS AND ADHERENCE TO TREATMENT FOR SLE PATIENTS

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Background: At the LUPUS EUROPE [forward abbreviated with LE] 2013 Convention in Paris, Professor N. Costedoat-Chalumet illustrated to the participants the critical issue of adherence to treatment (or more precisely, the lack of it). For many reasons, adhering to the prescribed treatment is a challenge for people living with Lupus, yet, "medicine only works if you take it". Understanding this area is critically important to helping people with lupus improve their quality of life. **Objectives:** In LE, we wanted to know the reason(s) for this lack of adherence and how to improve it. Is lack of access also a reason for not adhering to treatment? **Methods:** Two patient panels were formed to conduct in depth discussion about treatment. For each panel we invited people from our European community through our member groups. The panels were organised to represent different aspects like gender, age, time of diagnosis, main disease area and representing different countries. It was important to LE, that both patient panels were conducted by and for people living with lupus, which gives the participants a feeling of security and being understood: this is very important if you want them to share their experiences openly. LE organised the first patient panel on November 2nd-4th 2015, bringing together 10 people living with lupus, from 7 countries, to share their experience about "treatment", with a view to help improving the quality of life of people living with lupus. The second patient panel took place on March 11-13, 2016 bringing together 9 lupus affected people from all over Europe to further explore the burden of living with lupus, and to dive into the burden of daily treatment. The panels were conducted through a series of interactive presentations, team discussions and working groups. **Results:** The key findings of both patient panels were: 1. Because "Treatment" is broad; it is both medicine based and non-drug based, and can be categorised in three ways – core, medical, and well-being; there needs to be a more holistic approach to the patient. 2. Access includes ease of contact with Health Care Practitioners, support services such as orthotics and quality information as well as availability of medicines. 3. Patients will take new medicine, provided they understand the reasons why and the side effects. 4. Each patient is responsible for their own treatment and must realise that a positive mind-set can be decisive for the treatment of the disease. 5. Patient Organisations have a critical role to play, creating a community, sharing reliable information, providing hope, raising awareness and advocating for lupus. **Conclusions:** Organising a patient panel with a small closed group of patients on neutral ground in a "safe" environment has proven to be a good way of getting the patients to speak openly about a difficult subject and to reveal things, that they might not tell the health professionals. Through this initiative LE has gathered important information about access and adherence to treatment that we can now use to make suggestions about treatment and implement into our strategic plan for the years to come. **Disclosure of Interest:** None declared **DOI:** 10.1136/annrheumdis-2017-eular.2541

OP0281-PARE EDUCATING PATIENT EXPERTS/PATIENT PARTNERS – A NEW WAY

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Background: Patients general well-being is largely dependent on health care professionals. The education of these is therefore very important. It is more and more common using patients in the education of health care professionals. The Universities in Cyprus together with other health professional groups have shown interest in involving patients with RheumatMusculoSkeletalDiseases (RMDs) in the education of medical school students regarding RMDs. Besides discussing the disease, they will also learn about the obstacles faced by the patients as well as the impact on their daily life. Through this initiative, the hope is that early recognition and diagnosis is promoted as well as enhancing the knowledge and skills of future doctors. **Objectives:** The aim of this project was to implement a Patient Expert project in Cyprus League Against Rheumatism (CYPLAR), and through it train RMD patients to educate medical students and other healthcare professionals regarding