

FRIDAY, 16 JUNE 2017

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

S. Crisostomo¹, M. Santos¹, M. Serapioni², A.R. Matos², E.F. Mateus³ on behalf of MAIS PARTICIPAÇÃO, melhor saúde. ¹GAT - Grupo de Ativistas em Tratamentos, Lisboa; ²Centro de Estudos Sociais da Universidade de Coimbra, Coimbra; ³Liga Portuguesa Contra as Doenças Reumáticas, Lisboa, Portugal

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.

References:

- [1] Direção-Geral da Saúde – Ministério da Saúde. Plano Nacional de Saúde 2012–2016. Lisboa, Portugal; 2012.
- [2] Direção-Geral da Saúde – Ministério da Saúde. Plano Nacional de Saúde – Revisão e Extensão a 2020. Lisboa, Portugal; 2015.
- [3] European Patients Forum. The Value+ Policy Recommendations: Patient Involvement in Health Programmes and Policy [Internet]. Available from: http://www.eu-patient.eu/globalassets/projects/valueplus/doc_epf_policyrec.pdf.
- [4] European Patients Forum. Patient Empowerment Campaign [Internet]. Available from: <http://www.eu-patient.eu/campaign/PatientsprescribE/>.
- [5] International Alliance of Patients' Organisations. Policy statement. Patient Involvement [Internet]. 2005. Available from: <http://iapo.org.uk/sites/default/filesfiles/IAPO Policy Statement on Patient Involvement.pdf>.
- [6] Terzi A. The patients' involvement in health policies in Europe. Roma; 2013.

Disclosure of Interest: S. Crisostomo Grant/research support from: Abbvie, Bristol-Meyers Squibb, Janssen, GSK, Pfizer, Roche and Viiv, M. Santos Grant/research support from: Abbvie, Bristol-Meyers Squibb, Janssen, GSK, Pfizer, Roche and Viiv, M. Serapioni: None declared, A. Matos: None declared, E. Mateus: None declared

DOI: 10.1136/annrheumdis-2017-eular.5980

OP0277-PARE INITIAL INFORMATION PACKAGE FOR CHILDREN DIAGNOSED WITH JIA

T. Pakkala, M. Ekroth. Finnish Rheumatism Association, Helsinki, Finland

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.

Acknowledgements: Abbvie, Pfizer, BMS, Roche, The Finnish Society for Rheumatology and the Finnish Society of Rheumatology Nurses, Åberg Express, TNT Finland, Handitec, Paintek, Anglo-Nordic and of course all the individual persons, who helped with the project.

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2017-eular.2185

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

L. Grange^{1,2}, F. Rannou³, F. Berenbaum⁴, C. Roques⁵, F. Srour⁶, C. Delaunay⁷, P. Niemczynski⁸, C. Dreux⁹, P. Richette¹⁰, P.-A. Joseph¹¹, C. Cochet¹², J. Giraud¹³, F. Alliot Launois¹⁴, C. Gérard¹⁵ on behalf of the French National League Against Osteoarthritis. ¹President, AFLAR, Paris; ²Rheumatology, CHU Grenoble Alpes, Echirolles Cedex; ³SOFMER, SOFMER French society of physical medicine and rehabilitation; ⁴President, Sfr French Society of Rheumatology; ⁵AFRETH French Association for Thermal Res; ⁶CNOMK French Natl. order Council of the physio Therapists; ⁷SOFcot French Society of Orthopedic Surgery and Traumatology; ⁸11ONPP Natl. French Order Council of the Pedicure Podiatrist; ⁹Cespharm, CONP Natl. Council of the Coll. of Pharmacists; ¹⁰SFR french society of Rheumatology, Paris; ¹¹Division of Physical Medicine and Rehabilitation, University Hospital Pellegrin, Bordeaux; ¹²ONPP Natl. French Order Council of the Pedicure Podiatrist; ¹³Empatient; ¹⁴Vice Presidente; ¹⁵Treasurer, AFLAR, Paris, France

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