Innovations in arthritis health care

AB1483-PARE DEVELOPMENT AND ADAPTATION OF RHEUMABUDDY FOR YOUNG PEOPLE WITH JIA, THEIR FAMILIES AND PEOPLE WITH RA RESIDING IN THE UK

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Background: The number of children and young people (CYP) with JIA needing support is on the increase as available allied services continue to face cuts and are under more pressure than ever. A valuable life skill for any CYP with a long-term condition is self-management, the ability to control emotions, learn resilience, communicate, work toward goals and ultimately improve their physical and emotional wellbeing.

Methods: Rheumabuddy is a Danish app developed for children (aged over 12) adults in Denmark with RA. We were approached by the developers, Daman, in June 2016 and meetings and discussions followed regarding NRAS launching and distributing this innovative app in the UK. For a JIA audience, our main concerns were online child safety issues and whether the app could be used by younger children with JIA with their parents as well as by adults with RA. A survey of parents and young people with JIA and RA followed and after discussions with pilot users some adaptations were made, and child safety protection protocols were put in place between NRAS and Daman.

Results: Daman appointed NRAS as its UK partner and NRAS undertook a soft launch of Rheumabuddy in November 2017.

Conclusions: Since its launch, to date we have 2000 active users who are a mixture of children with JIA and their parents, adults with JIA and adults with RA. Here are some quotes from users:

"Rheumabuddy has been so helpful and I am now able to track my progress which I can show my consultant. I would often forget how I felt 3 or 4 months ago"

"The Rheumabuddy app was a way for my daughter to let me know how she felt each day, normally she doesn't like discussing it"

We know that CYP are growing up in a challenging and fast changing world. The ability to use self-management strategies effectively is a skill that becomes very important for success as children grow into adulthood yet is hard to acquire through the NHS alone. Rheumabuddy encourages the self-monitoring and regular recording of key patient reported outcomes. Changes in symptoms over time can be displayed in graph format and can be shared with HCP's, family, and school. The collation of cumulative data around mood, pain and fatigue can, for example, lead to empowerment of the individual or family resulting in ability to effect positive lifestyle change in the person with JIA or RA.

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Best practice campaigning

AB1484-PARE FORMING PROGRESSIVE PATIENT ALLIANCES FOR PROGRESSIVE THINKING

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Background: The role and scope of influence of patient organisations has been undeniably increasing. Wilson 1999 Patients are in the lead of influencing the decision-making processes in healthcare and in doing so, forming strategic and constructive alliances through umbrella organisations can be of great value. This article discusses the benefits of forming progressive alliances between RMDs patient organisations using the example of the partnership between Agora and the Global Alliance for Patient Access (GAfPA). The data presented has been drawn from the first joint project between Agora and GAfPA (2017) in an effort to raise awareness about access to Biosimilar and Biologic medicine, in combination with developing self-management skills in the sense of a holistic model for treating and managing RMDs.

Objectives: The objectives of the joint project were to provide patient groups with a greater understanding of the current policy landscape for Biologic and Biosimilar medicines in Europe; equip patients with effective tools to inform policymakers about patient concerns; kick-start the

establishment of an advocacy platform for the Agora organisations; and to examine the role of self-management programmes in supporting patients with RMDs along with the use of technology (HTA). The main objective of this article is to examine the role of strategic alliances in creating a strong patient front that seeks to become part of the decision-making processes and influence policy changes on national and EU levels. Auch alliances offer patients a new perspective and a progressive way of thinking healthcare matters.

Methods: Keynote presentations and group discussions were carried out. The patients who participated in the workshop were exposed to the fundamental information about the use of Biologic and Biosimilar medication and related policy issues and were engaged in a discussion that eventually led to the composition of a position paper with concrete principles on the use of this treatment.

Results: Agora and GAfPA have published the "Patients Principles around the use of Biologics and Biosimilars", which was disseminated amongst the Agora members and has been used to raise awareness about the specific topic in each country-member.

Conclusions: The alliance between Agora and GAfPA has enabled Agora to strengthen its advocacy efforts and focus towards becoming more active in monitoring policy changes. There was a strong consensus that the patient voice should be central to all discussions about commencing or switching treatments and that shared decision making should always be an integral part of the process. The collaboration between national and umbrella organisations has created a strong network of patients, who share similar ideas, principles and support each other towards advocating for patients' rights to a higher quality of life. These principles would certainly be of interest to EULAR PARE members and other patient organisations beyond the immediate AGORA/GAfPA network, who could consider using them in their own advocacy work and/or when supporting individual patients in their organisations.

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AB1485-PARE REUMANIFEST: JOINING FORCES FOR POLITICAL URGENCY

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Background: In 2012, health insurance provisions for people with RMDs were cut drastically when reimbursement of physical therapy under the Dutch basic health insurance package was scrapped for reasons including lack of scientific evidence, the economic crisis and rising healthcare costs. The effect has been counterproductive. Costs have gone up as more patients use more medication and visit their rheumatologist and other specialists more often. It has also led to patients not getting the care they need. Because the Dutch Arthritis Foundation (DAF) believes that patients with RMDs should have access to the care they need, it launched a lobby to influence key governmental and political stakeholders.

Objectives: According to the DAF, patients with RMDs need access to the physical therapy they need. Efforts made in this area, such as the introduction of a registration point and impact research to demonstrate the effect of decreased accessibility, remained unsuccessful. We needed to adopt a different approach to instil in the government and political stakeholders a sense of urgency and to raise general awareness of the issue.

Methods: Parties in the field of RMD have now joined forces by:

- consulting patients and care providers in a national survey: "Why is physiotherapy important to you?"
- drafting a Reumanifest in which patients, doctors and researchers lobby for reinstatement of physiotherapy in the basic medical insurance package.
- having the Reumanifest signed by patients, caregivers, professional organisations, professors, and other patient organisations (more than 25 000 responses).

Results: The Reumanifest was presented to political parties as a petition, and appeared in newspapers as an advertisement. This led to critical questions being asked to the Dutch Minister of Health, and put the issue

and its urgency firmly back on the political agenda. With renewed political pressure on the issue, we expect that this will eventually lead to a solution for people with RMDs who need physiotherapy, but who now have to pay for this privately. The campaign has increased awareness among the cabinet and other political stakeholders.

Conclusions: By joining forces, you can make your voice heard in politics, as support from various perspectives lends credibility and relevance to the urgency.

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