and so we did. In the end, the Academic Board accepted our proposal. The program runs on students in the fourth Academic Year, in small groups, and on the premises of the school. The other one with postgraduate Medical Students didn’t accept the proposal of our program, with the justification that as a department of a foreign medical school, they couldn’t implement anything in the students program. So far, more than 10 trainings have been conducted. At the end of the first year that the program was implemented, the Medical School asked from the organisation for a Patient Instructor to take part at the Musculoskeletal Examination and be a model for the Examination. Seeing our success, and taking into consideration the students’ evaluation of the program, especially the fact that 95% of them said, ‘it was very important for them to have a Patient Expert Program during their studies’ our organisation decided to explain our collaboration with more Healthcare Professions Universities. Our original goal had been to collaborate with one of the medical schools/universities, but now we have bigger plans. Now we want this program to be established in all the universities in the country with the Patient Expert RMD’s program implemented in all health professions curriculums.

Conclusion: The importance of the Patient Expert in RMD’s is unquestionable. Patient Expert Program is an excellent tool to raise awareness on RMD’s. Also it is very helpful for the Medical or Health care Professions student as it can help them better understand the disease and the patients. The success of the program is also giving motivation to the organisation to expand and improve the program. It also shows the significance of the program for the next generation of Physicians and Healthcare Professionals. Our organisation is leading in patient centered care and is proof that making the patient the most important is the target of treatment for RMD’s in our country.

Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2020-eular.2111

WORLD YOUNG RHEUMATIC DISEASES (WORD) DAY: THE FIRST INTERNATIONAL AWARENESS DAY FOR PAEDIATRIC RHEUMATIC DISEASES

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Background: There is a lack of awareness of paediatric rheumatic diseases (PRDs), among the public, and certain groups of healthcare professionals, such as general practitioners [1]. To help improve awareness and understanding of PRDs, World Young Rheumatic Diseases Day (WORD Day) was established in 2019.

Objectives: The aim of WORD Day, which took place on 18 March 2019, was to raise awareness of PRDs, while informing young people, families, healthcare professionals, teachers, and the public about the importance of timely referral plus early diagnosis and access to appropriate treatment and support.

Methods: A steering committee was established for the inaugural campaign. An external agency was appointed to provide digital support, with an official social media campaign launching in December 2018. Social media analytics were used to measure the impact of official social media platforms. A range of branded materials were also made available (Fig 1), including an official campaign video. In addition, a specific engagement activity (#ButtonChallenge2019) was launched. This challenged participants to button up a piece of clothing while wearing gloves, to simulate the difficulties that young people with PRDs face undertaking daily activities. As part of the campaign launch, a list of suggested activities were provided, along with template press releases.

Results: Several face-to-face and virtual events took place globally on or around WORD Day 2019, with 34 countries reporting events (Fig 2). Examples of events included lectures, social gatherings and media appearances. An official WORD Day tweet chat was also hosted. Regarding social media impact, between December 2018 and March 2019, a total of 2,585 and 660 individuals followed the official Facebook and Twitter accounts, respectively. Facebook posts were seen 646,000 times since the start of the campaign, with over 60,000 of Facebook reach from posts published on 18 March 2019 exclusively. A total of 270,800 impressions were observed on Twitter. The official #WORDay2019 hashtag was seen by 533,955 unique accounts on 18 March 2019 alone, with 3,334,699 impressions. Posts with the hashtag were retweeted 1,112 times on WORD Day, with a total of 1,568 tweets recorded that day. With regards to the #ButtonChallenge2019, the challenge video was viewed for 6,700 minutes and received participation from across the world. Compared to the industry benchmark, the average engagements per post for WORD Day-related content was significantly higher compared to other medical and non-for-profit social media pages.

Conclusion: WORD Day 2019 was the first international campaign focused solely on PRDs. Organic and paid social media content aided the dissemination of the WORD Day message, with Facebook proving to be the most popular social platform. Despite a wealth of different content published, authentic materials, namely video content, proved to be the most popular with users, particularly when it featured material designed by and with young people with PRDs. It was demonstrated that awareness events can often be resource-light and easily implemented across a range of diverse countries. It is anticipated that the global reach of WORD Day will increase over time as the campaign becomes more established.


Acknowledgments: PRcS for their financial support.

DOI: 10.1136/annrheumdis-2020-eular.1794

EXPERIENCE EXCHANGE – FUNDRAISING AND PATIENT EXPERT PROGRAM

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Background: Since the establishment of ORS, we have been organising different events for rheumatic diseases patients and their supporters within our five branches. After celebrating our 10th anniversary in 2017 we were keen to expand and improve our activities, learning from an organisation with long tradition, in order to strengthen our position and to start reaching another level – growing from a small to a medium-sized organization in the next three years.

The main source of our income were the pharmaceutical companies (94%). We wanted to reduce their contribution to our budget by 20% in the next three years. We had established good cooperation with two medical high schools and we would like to consider cooperation with a medical faculty. We were keen to gain insight into the Patient Expert Programme (PEP) project that Swedish Rheumatism Association had developed and hoped to then begin and steadily develop
From 14th October-16th October 2019 Swedish delegation (president, two trainers) activities of their association.

Methods: The aims of this knowledge transfer programme were for us to:

1. Fundraising
   - Learn how to gather more voluntary contributions of money and other resources. Following the knowledge transfer visits we will organise a seminar to disseminate information with the representatives of all our branches. After the seminar our activists will have been trained to collect money for different activities. Those activities will attract more members and provide better life for people with RMDs.

2. Patient Expert Program
   - Implement the Patient Expert Program. The implementation of this program would strengthen the connections with medical institutions, provide first-hand knowledge for future doctors, provide better care for RMDs patients in the future. The PEP will allow the organization to collaborate closer with the universities, the doctors, researchers, health professionals.

3. Cooperation among sister organisations
   Develop strong relationships with the sisters EULAR organisations.

From 23th January-26th January 2020 two trainers from Sweden came to Serbia to do the two-days PEP training as well as the visits to relevant institutions.

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Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2020-eular.4864

OP0262-HPR BIOSIMILAR SWITCHING PROCESS - UK PATIENTS’ EXPERIENCE STUDY

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Background: The introduction of 4 adalimumab biosimilars was challenging for the health service and patients alike. A group of patient organisations representing rheumatology, dermatology and gastroenterology patients worked with NHS England in producing materials for disseminating information to prescribers and patients to ensure smooth and appropriate transition to biosimilar products from the originator product as appropriate. These patient groups wanted to know how the ‘switch’ process was implemented and if shared decision making was practiced.

Objectives: To gather patient feedback on biosimilar switch process and report findings back to NHS England as well as provide the patient organisations information to develop any future resources to help improve patient and physician shared decision making.

Methods: A working group of the 4 organisations collaborated on designing an online survey asking questions around how the individual was communicating with regarding their treatment being switched to a biosimilar; was there any choice or perceived input into the decision making process; how queries or issues were handled and overall satisfaction on how the individual felt their personal preferences/needs were met.

Results: 899 usable responses were gathered representing 52% Rheumatology patients; 42% Gastroenterology patients and 5% Dermatology patients with remaining 1% more complex specialties. More than half of patients were not asked for their consent before their treatment was switched to a biosimilar of adalimumab with only 40% giving consent 7% couldn’t remember or were unsure if consent was given. 75% were not at all satisfied or not satisfied with the ability to decline being switched with only 12% feeling that they had been given an option to decline being switched.

Conclusion: Shared Decision Making (SDM) needs to be put into action not just words. There is a clear majority that are dissatisfied with the communication they had prior to the switch and are very dissatisfied with the lack of patient engagement in the decision-making process. NRAS, NASS, Crohn’s & Colitis UK and the Psoriasis Association will continue to collaborate with NHS England and other stakeholders as appropriate to make Shared Decision Making a reality not just rhetoric.

Acknowledgments: National Axial Spondyloarthritis Society UK; Crohns’ & Colitis UK; Psoriasis Association, UK; National Rheumatoid Arthritis Society

Disclosure of Interests: Clare Jacklin Grant/research support from: NRAS has received grants from pharmaceutical companies to carry out a number of projects. Consultant of: I have been paid a speakers fee to participate in advisory boards, in house training of staff and health professional training opportunities, Speakers bureau: Various pharma companies, Alisa Bosworth Speakers bureau: a number of pharmaceutical companies for reasons of inhouse training, advisory boards etc.

DOI: 10.1136/annrheumdis-2020-eular.2362

Disease consequences...

OP0261-PARE BIOSIMILAR SWITCHING PROCESS - UK PATIENTS’ EXPERIENCE STUDY

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Background: The introduction of 4 adalimumab biosimilars was challenging for the health service and patients alike. A group of patient organisations representing rheumatology, dermatology and gastroenterology patients worked with NHS England in producing materials for disseminating information to prescribers and patients to ensure smooth and appropriate transition to biosimilar products from the originator product as appropriate. These patient groups wanted to know how the ‘switch’ process was implemented and if shared decision making was practiced.

Objectives: To gather patient feedback on biosimilar switch process and report findings back to NHS England as well as provide the patient organisations information to develop any future resources to help improve patient and physician shared decision making.

Methods: A working group of the 4 organisations collaborated on designing an online survey asking questions around how the individual was communicating with regarding their treatment being switched to a biosimilar; was there any choice or perceived input into the decision making process; how queries or issues were handled and overall satisfaction on how the individual felt their personal preferences/needs were met.

Results: 899 usable responses were gathered representing 52% Rheumatology patients; 42% Gastroenterology patients and 5% Dermatology patients with remaining 1% more complex specialties. More than half of patients were not asked for their consent before their treatment was switched to a biosimilar of adalimumab with only 40% giving consent 7% couldn’t remember or were unsure if consent was given. 75% were not at all satisfied or not satisfied with the ability to decline being switched with only 12% feeling that they had been given an option to decline being switched.

Conclusion: Shared Decision Making (SDM) needs to be put into action not just words. There is a clear majority that are dissatisfied with the communication they had prior to the switch and are very dissatisfied with the lack of patient engagement in the decision-making process. NRAS, NASS, Crohn’s & Colitis UK and the Psoriasis Association will continue to collaborate with NHS England and other stakeholders as appropriate to make Shared Decision Making a reality not just rhetoric.

Acknowledgments: National Axial Spondyloarthritis Society UK; Crohns’ & Colitis UK; Psoriasis Association, UK; National Rheumatoid Arthritis Society

Disclosure of Interests: Clare Jacklin Grant/research support from: NRAS has received grants from pharmaceutical companies to carry out a number of projects. Consultant of: I have been paid a speakers fee to participate in advisory boards, in house training of staff and health professional training opportunities, Speakers bureau: Various pharma companies, Alisa Bosworth Speakers bureau: a number of pharmaceutical companies for reasons of inhouse training, advisory boards etc.

DOI: 10.1136/annrheumdis-2020-eular.2362

Disease consequences...