Personal patient stories were leveraged throughout the campaign by the involvement of #SeeMe Ambassadors. These were children and young people living with JIA who were willing to share their experience publicly. National and regional media were successfully targeted, securing considerable coverage. Subsequently, the campaign progressed to a third phase of activity as young people raised awareness of JIA through their own schools, social clubs and social media networks.

An infographic was developed to communicate key medical information about JIA and paediatric rheumatology services in a clear, accessible way.

Results: #SeeMe received an overwhelmingly positive response, not just from those affected by JIA, but from the general public, the medical community and political stakeholders. The campaign was successful in the following measurable ways:

- 87,000 people viewed the campaign video;
- 17,000 people signed the #SeeMe petition;
- 820,000 people were reached by the social media campaign;
- 35 pieces of media coverage on television, radio and print were achieved;
- Lobbying of politicians by patients and their families prompted 12 TDs and senators to raise this issue;
- In May 2018, the Government committed to the appointment of an additional paediatric rheumatologist in 2019, with plans to recruit a multidisciplinary team.

Conclusion: This campaign set out to give a voice to those living with JIA and to increase awareness and understanding of the disease. The campaign highlighted the challenges in paediatric rheumatology services and proved an effective vehicle in harnessing public opinion; resulting in over 17,000 people signing the petition calling for the implementation of the Model of Care for Paediatric Rheumatology.

In the wake of the campaign, the announcement by the Irish Government to invest in paediatric rheumatology services represents an important step forward. While much remains to be done, this is progress and highlights the important role played by patient organisations, and their public education and advocacy work.

Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2019-eular.4741

SATURDAY, 15 JUNE 2019

Tackling inflammatory bone disorders in children and adults

OP0342

IDENTIFYING CANDIDATE ITEMS TOWARDS THE DEVELOPMENT OF CLASSIFICATION CRITERIA FOR CHRONIC NONBACTERIAL OSTEOMYELITIS (CNO) AND CHRONIC RECURRENT MULTIFOCAL OSTEOMYELITIS (CRMO)

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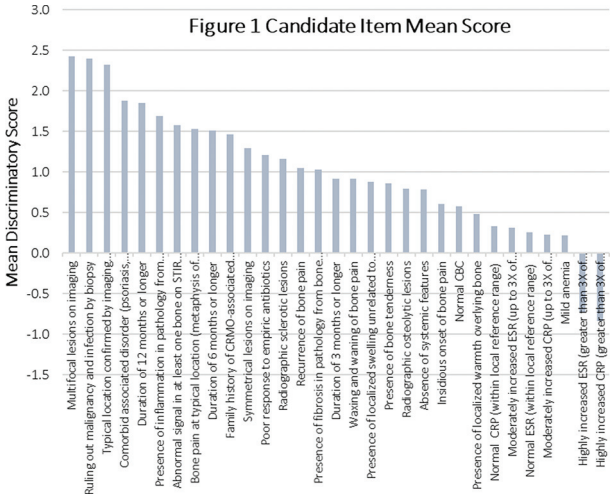
Background: Chronic nonbacterial osteomyelitis (CNO) is a severe and occult autoinflammatory bone disease of unknown cause. Early diagnosis is challenging, and CNO may debilitate affected children when left untreated. Currently, evidence-based and validated diagnostic and classification criteria for CRMO/CNO are lacking. The insidious disease course, increasing disease incidence, and significant delay in diagnosis highlight the need for the development of classification criteria that leads to more precise and early selection of patients for clinical trials[1,2].

Objectives: To identify candidate items towards developing classification criteria for CNO using anonymous survey and nominal group technique.

Methods: An international collaborative effort was formed within the pediatric and adult rheumatology communities to conduct the following phases: 1) to generate candidate criteria items by a Delphi survey among international rheumatologists; 2) to reduce candidate criteria items through consensus processes involving physicians managing CNO and patients or caregivers of children with CNO. This study was approved by Seattle Children's Hospital Institutional Review Board.

Results: In Phase 1, 259 pediatric rheumatologists (30%, N=865) participated in an online questionnaire about features most relevant to the classification of CNO. Of those, 77 (30%) practiced in Europe, 132 (51%) in North America, and 50 (19%) in other continents. A total of 138 (53%) responders had >10 years of practicing experience and 108 (42%) had managed >10 CNO patients. There were 33 candidate criteria items initially identified. In Phase 2, candidate items were presented to 39 rheumatologists and 7 parents and items were refined or eliminated through item reduction techniques. Seventy-seven (94%, N=82) workgroup members then participated in a second survey to rank the remaining items by their distinguishing power of CNO from mimicking conditions. Figure 1 shows the mean score for the remaining 31 candidate criteria. Multifocal lesions, ruling out malignancy and infection and typical location on imaging had the greatest means. CRP and/or ESR greater than 3x the normal upper limit had the greatest negative means.



Discriminatory Score: +3/-3 (increases/decreases the likelihood of CRMO the most)
+2/-2 (increases/decreases the likelihood of CRMO moderately)
+1/-1 (increases/decreases the likelihood of CRMO slightly)
0 (no difference)

Conclusion: Through surveys and consensus technique, candidate items towards developing classification criteria for CNO were identified. This list of items will guide the design of a feasible patient data collection form towards weighting of each item in the classification criteria.

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Acknowledgement: CNO/CRMO Work Group, Childhood Arthritis and Rheumatology Research Alliance

Disclosure of Interests: Melissa Oliver: None declared, Eveline Wu: None declared, Raymond Naden Speakers bureau: Was a speaker at conferences paid by pharmaceutical companies several times in the past, but not in the last 7 years., Matthew Hollander: None declared, Polly Ferguson: None declared, Fatma Dedeoglu Consultant for: Attended a scientific meeting for Novartis in 2017. Overall monetary amount was less than $5000., Seza Özen Consultant for: Seza Ozen is receiving consultancy fees from Novartis, Speakers bureau: Roche, Yongdong Zhao Grant/research support from: I have grant support from Bristol-Myer Squibb

DOI: 10.1136/annrheumdis-2019-eular.1539

SATURDAY, 15 JUNE 2019

To image or not to image in spondyloarthritis?

OP0343 LONGITUDINAL ASSESSMENT OF MRI OF THE SACROILIAC JOINTS IN THE ASAS CLASSIFICATION COHORT: EVOLUTION OF DIAGNOSTIC FEATURES AND PREDICTIVE UTILITY FOR AXIAL SPONDYLOARTHRITIS:

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Background: Follow up of the ASAS Classification Cohort (CC) indicated a high positive predictive value for the ASAS classification criteria derived from baseline patient and imaging data[1]. Moreover, diagnosis of axSpA was changed by the rheumatologist in only 11.2% of patients after 4.4 years. This has raised potential concerns regarding diagnostic ascertainment bias.
Objectives: To determine the evolution of MRI features of axSpA in ASAS-CC cases by central readers, whether this reflects diagnostic assignment by the rheumatologist, and the predictive utility of baseline MRI features of axSpA.
Methods: MR images were available from 108 cases in the ASAS-CC at baseline and follow up (mean 4.4 years) and also had a rheumatologist diagnosis at both time points. Eight readers from the ASAS MRI group recorded MRI lesions that comprised global assessment (MRI indicative of axSpA (yes/no), active and/or structural lesion typical of axSpA (yes/no) according to ASAS definitions), ASAS definition of positive MRI, and detailed scoring of lesions per SIJ quadrant (SPARCC SIJ method). MRI data from ≥2 readers and from the majority of readers (≥5/8) was used to calculate positive and negative predictive values (PPV, NPV).

Table 1

Rheumatologist's diagnosis	MRI is indicative of axSpA (≥ 2 readers)			
	Yes at baseline and yes at follow up (N =48)	Yes at baseline and no at follow up (N = 4)	No at baseline and yes at follow up (N =6)	No at baseline and No at follow up (N = 50)
SpA yes at baseline and follow up (N= 82)	46 (56.1%)	2 (2.4%)	4 (4.9%)	30 (36.6%)
SpA yes at baseline and no at follow up (N = 4)	1 (25%)	1 (25%)	0 (0%)	2 (50%)
SpA no at baseline and yes at follow up (N =5)	1 (20%)	0 (0%)	1 (20%)	3 (60%)
SpA no at baseline and no at follow up (N =17)	0 (0%)	1 (5.9%)	1 (5.9%)	15 (88.2%)

Taleb 2

MRI scan at baseline	Rheumatologist Diagnosis of axSpA at follow up n=108			
	Sensitivity	Specificity	PPV (%)	NPV (%)
Active lesions typical of axSpA (≥2 readers)	48.3 (37.4-59.2)	100.0 (83.9-100.0)	100.0	31.8
Active lesions typical of axSpA (≥5/8 readers)	40.2 (29.9-51.3)	100.0 (83.9-100.0)	100.0	28.8
Structural lesions typical of axSpA (≥2 readers)	48.3 (37.4-59.2)	90.48 (69.6-98.9)	95.5	29.7
Structural lesions typical of axSpA (≥5/8 readers)	31.0 (21.5-41.9)	95.2 (76.2-99.9)	96.4	25.0
ASAS positive MRI (≥2 readers)	46.0 (35.2-57.0)	100.0 (83.9-100.0)	100.0	30.9
ASAS positive MRI (≥5/8 readers)	40.23 (29.9-51.3)	100.0 (83.9-100.0)	100.0	28.8
MRI indicative of axSpA (≥2 readers)	56.3 (45.3-66.9)	85.7 (63.7-97.0)	94.2	32.1
MRI indicative of axSpA (≥5/8 readers)	50.6 (39.6-61.5)	100.0 (83.9-100.0)	100.0	32.8

Results: MRI was considered diagnostic of axSpA in 52/108 (48.1%) cases at baseline and in 47/86 (54.7%) diagnosed at baseline as axSpA by the rheumatologist. Change in MRI diagnosis was recorded in 10/108 (9.3%) of cases (2 from yes to no, and 4 from no to yes for axSpA) according to agreement by ≥2 readers and in only 3 cases according to ≥5/8 readers (Table 1). Change in rheumatologist diagnosis was recorded in 9/108 (8.3%), 2 of which had a change in MRI diagnosis. Baseline MRI lesions considered typical of axSpA had very high PPV for follow up diagnosis of axSpA (Table 2).
Conclusion: The infrequent change in diagnostic ascertainment of rheumatologists over follow up of the ASAS-CC is supported by this central reader evaluation of MRI scans. A positive MRI at baseline had very high PPV for a follow up diagnosis of axSpA.

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Disclosure of Interests: Walter P Maksymowych Grant/research support from: AbbVie, Pfizer, Janssen, Novartis, Consultant for: AbbVie, Eli Lilly, Boehringer, Galapagos, Janssen, Novartis, Pfizer and UCB Pharma; Chief Medical Officer for Canadian Research and Education Arthritis, Xenofon Baraliakos Grant/research support from: AbbVie, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene, Centocor, Chugai, Janssen, MSD, Novartis, Pfizer Inc, Roche and UCB, Grant/research support from: AbbVie, Pfizer, Merck Sharp & Dohme, UCB Pharma, Novartis, Consultant for: AbbVie, Bristol-Myers Squibb, Boehringer Ingelheim, Celgene, Chugai, Janssen Biologics, Novartis, Pfizer, UCB Pharma, Galapagos, Speakers bureau: AbbVie, Chugai, Janssen, Novartis, Pfizer, UCB Pharma, Manouk de Hooge: None declared, Iris Eshed: None declared, Susanne Juhl Pedersen: None declared, Ulrich Weber Consultant for: Abbvie, Joachim Sieper Consultant for: Abbvie, Böhringer Ingelheim, Janssen, Lilly, Merck, Mylan, Novartis, Pfizer, UCB., Speakers bureau: Abbvie, Böhringer Ingelheim, Janssen, Lilly, Merck, Mylan, Novartis, Pfizer, UCB., Stephanie Wichuk: None declared, Denis Poddubnyy Grant/research support from: AbbVie, Merck Sharp & Dohme, Novartis, Consultant for: AbbVie, Bristol-Myers Squibb, Janssen, Merck Sharp & Dohme, Novartis, Pfizer, UCB Pharma, Speakers bureau: AbbVie, Bristol-Myers Squibb, Janssen, Merck Sharp & Dohme, Novartis, Pfizer, Roche, UCB Pharma, Joel Paschke: None declared, Robert G Lambert Consultant for: Bioclinica, Parexel, Abbvie, Mikkel Østergaard Grant/research support from: Abbvie, Celgene, Centocor, Merck, Novartis, Consultant for: Abbvie, BMS, Boehringer-Ingelheim, Celgene, Eli Lilly, Hospira, Janssen, Merck, Novartis, Novo, Orion, Pfizer, Regeneron, Roche, and UCB, Speakers bureau: Abbvie, BMS, Boehringer-Ingelheim, Celgene, Eli Lilly, Hospira, Janssen, Merck, Novartis, Novo, Orion, Pfizer, Regeneron, Roche, and UCB
DOI: 10.1136/annrheumdis-2019-eular.7561

OP0344 WHICH MAGNETIC RESONANCE IMAGING LESIONS OF THE SACROILIAC JOINTS ARE OF DIAGNOSTIC VALUE FOR AXIAL SPONDYLOARTHRITIS?

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Background: Classification of patients as having axial spondyloarthritis (axSpA) by the imaging arm of the ASAS criteria relies partly on the detection of bone marrow edema (BME) suspicious of SpA on magnetic resonance imaging (MRI) of the sacroiliac joints (SIJ). Fatty lesions (FL) and erosions on SIJ-MRI have been suggested to be genuinely related to SpA in the context of interpretation of a 'positive' MRI in case of doubtful BME cases (1).
Objectives: Evaluate the role of different SIJ-MRI lesions for diagnosing axSpA in daily routine practice.
Methods: Consecutive patients with chronic back pain (duration >3 months) starting before age 45 and clinical suspicion of axSpA underwent a complete diagnostic workup including SIJ-MRI. All clinical, laboratory and imaging data were available to experienced rheumatologists for diagnosing axSpA or not (non-SpA). In parallel, two experienced readers, blinded to all patients´ information and diagnosis, evaluated the MRIs and made a diagnostic judgement based only on imaging. Furthermore, radiologists quantitatively assessed MRIs for BME (Berlin Score), FL, erosions, sclerosis and ankylosis.
Results: A total of 300 consecutive patients were recruited. AxSpA was diagnosed by the rheumatologist in 131 patients (43.7%) with mean age of 34.5±7.2 years, 73% HLA-B27+, mean symptom duration 58.6±69.5 months, vs. 169 non-SpA patients with mean age of 34.5±7.4 years, 21.3% HLA-B27+, mean symptom duration 33.9±45.1 months. The ASAS classification criteria were fulfilled by 99/131 patients diagnosed with axSpA (75.6%) vs. 70/169 patients diagnosed vs. non-SpA non-SpA (41.4%).