

**JDM working group research collaborative working document**

The following document lists current / proposed research studies and opportunities for collaborative working.

If you would like to add anything to this document, please contact the JDM working group secretary, Silvia Rosina: [SilviaRosina@gaslini.org](mailto:SilviaRosina@gaslini.org) or Chair, Charalampia Papadopoulou: [Charalampia.Papadopoulou@gosh.nhs.uk](mailto:Charalampia.Papadopoulou@gosh.nhs.uk)

**Research projects / collaborative working**

<b>Project</b>	<b>Inclusion</b>	<b>Contact</b>
Trial of JAK-STAT inhibitors for JDM.	Trial consortium helping to design trial & apply for funding.	Marc Jansen / Annet van Royen / Saskia Veldkamp. <ul style="list-style-type: none"> <li>• <a href="mailto:m.h.a.jansen@umcutrecht.nl">m.h.a.jansen@umcutrecht.nl</a></li> <li>• <a href="mailto:a.vanroyen@umcutrecht.nl">a.vanroyen@umcutrecht.nl</a></li> <li>• <a href="mailto:s.r.veldkamp-3@umcutrecht.nl">s.r.veldkamp-3@umcutrecht.nl</a></li> </ul>
JAKi survey – investigating current use / experience of JAKi for JDM.	PRoS / CARRA collaboration.	PRoS contact: Rebecca Nicolai; CARRA contacts: Stacey Tarvin/ Matt Sherman. <ul style="list-style-type: none"> <li>• <a href="mailto:rebecca.nicolai@opbg.net">rebecca.nicolai@opbg.net</a></li> <li>• <a href="mailto:starvin@iu.edu">starvin@iu.edu</a></li> <li>• <a href="mailto:matthew.sherman@nih.gov">matthew.sherman@nih.gov</a></li> </ul>
Extension of SHARE consensus for management of JDM – an international cross party initiative (IMACS, PRoS, CARRA).	IMACS SHARE SIG (open invite)	Liza McCann / Susan Kim / Adam Huber / Annet van Royen-Kerkof <ul style="list-style-type: none"> <li>• <a href="mailto:Liza.mccann@alderhey.nhs.uk">Liza.mccann@alderhey.nhs.uk</a></li> <li>• <a href="mailto:Susan.Kim@ucsf.edu">Susan.Kim@ucsf.edu</a></li> <li>• <a href="mailto:Adam.huber@iwk.nshealth.ca">Adam.huber@iwk.nshealth.ca</a></li> <li>• <a href="mailto:a.vanroyen@umcutrecht.nl">a.vanroyen@umcutrecht.nl</a></li> </ul>
JDM outcome measures – development of composite disease activity scores and parent/patient reported outcome measures (PROs)	Led by Gaslini institute	Angelo Ravelli / Silvia Rosina <ul style="list-style-type: none"> <li>• <a href="mailto:Angeloravelli@gaslini.org">Angeloravelli@gaslini.org</a></li> <li>• <a href="mailto:silviarosina@gaslini.org">silviarosina@gaslini.org</a></li> </ul>
Development of Treat to Target (T2T) strategy in JDM	Led by Gaslini institute - Steering Committee/Task Force/research fellows	Silvia Rosina, Angelo Ravelli, Brian Feldman <ul style="list-style-type: none"> <li>• <a href="mailto:Angeloravelli@gaslini.org">Angeloravelli@gaslini.org</a></li> <li>• <a href="mailto:silviarosina@gaslini.org">silviarosina@gaslini.org</a></li> <li>• <a href="mailto:brian.feldman@sickkids.ca">brian.feldman@sickkids.ca</a></li> </ul>
Sleep disturbances & fatigue in children with JDM	Pilot at GOSH prior to wider invite.	Charris Papadopoulou <ul style="list-style-type: none"> <li>• <a href="mailto:Charalampia.Papadopoulou@gosh.nhs.uk">Charalampia.Papadopoulou@gosh.nhs.uk</a></li> <li>• <a href="mailto:Meredyth.wilkinson.14@ucl.ac.uk">Meredyth.wilkinson.14@ucl.ac.uk</a></li> </ul>
Promote education and training in JDM, including PRoS / EULAR course (annual updates – McCann / Almeida), PRoS Knowledge Based Exam, & learning resources (meetings / webinars & website information) which may include resources for patients and parents.	PRES core group / EMERGE members / patient and parent groups	Brigitte Bader-Meunier / Raquel Campanilho-Marques / Liza McCann / Beverley Almeida <ul style="list-style-type: none"> <li>• <a href="mailto:brigitte.bader-meunier@aphp.fr">brigitte.bader-meunier@aphp.fr</a></li> <li>• <a href="mailto:raquelpcmarques@gmail.com">raquelpcmarques@gmail.com</a></li> <li>• <a href="mailto:Liza.mccann@alderhey.nhs.uk">Liza.mccann@alderhey.nhs.uk</a></li> <li>• <a href="mailto:Beverley.almeida@alderhey.nhs.uk">Beverley.almeida@alderhey.nhs.uk</a></li> </ul>
Promote collaboration / core dataset entry in myositis registries, including use of MYONET	Position statement available on website or visit	Liza McCann / Lucy Wedderburn <ul style="list-style-type: none"> <li>• <a href="mailto:Liza.mccann@alderhey.nhs.uk">Liza.mccann@alderhey.nhs.uk</a></li> <li>• <a href="mailto:l.wedderburn@ucl.ac.uk">l.wedderburn@ucl.ac.uk</a></li> </ul> <a href="https://www.myonet.info">https://www.myonet.info</a>

	(formally called Euromyositis).	MYONET website.	
	In collaboration with Health Professionals in Paediatric Rheumatology (HPPR) and IMACS interest group Rehab and exercise: Exercise training in JDM.	IMACS SIG – Exercise & Rehabilitation Group.	Sue Maillard: <a href="mailto:sue.maillard@gosh.nhs.uk">sue.maillard@gosh.nhs.uk</a>
	JDM Biomarker project	Open invite	Annet van Royen-Kerkof / Rebecca Nicolai / Brigitte Bader Meunier <ul style="list-style-type: none"> <li>• <a href="mailto:a.vanroyen@umcutrecht.nl">a.vanroyen@umcutrecht.nl</a></li> <li>• <a href="mailto:m.h.a.jansen@umcutrecht.nl">m.h.a.jansen@umcutrecht.nl</a></li> <li>• <a href="mailto:s.r.veldkamp-3@umcutrecht.nl">s.r.veldkamp-3@umcutrecht.nl</a></li> <li>• <a href="mailto:m.rodero@uq.edu.au">m.rodero@uq.edu.au</a></li> <li>• <a href="mailto:Brigitte.bader-meunier@aphp.fr">Brigitte.bader-meunier@aphp.fr</a></li> </ul>
	<b>Dysregulation of Type I interferon signalling in Juvenile Dermatomyositis: from systemic trigger to new muscle biomarker.</b>	French ANR application (2020)	Cyril.Gitiaux/ Mathieu Paul Rodero / Brigitte Bader Meunier <ul style="list-style-type: none"> <li>• <a href="mailto:Cyril.gitiaux@aphp.fr">Cyril.gitiaux@aphp.fr</a></li> <li>• <a href="mailto:m.rodero@uq.edu.au">m.rodero@uq.edu.au</a></li> <li>• <a href="mailto:Brigitte.bader-meunier@aphp.fr">Brigitte.bader-meunier@aphp.fr</a></li> </ul>
	<i>Physical Activity Among Children and Youth with Juvenile Dermatomyositis: A Cross-Sectional International Survey</i>	CARRA/ PReS / collaboration.	Kristin Houghton / Helga Sanner / Sue Maillard / K Risum. For PReS contacts: <ul style="list-style-type: none"> <li>• <a href="mailto:helga.sanner@medisin.uio.no">helga.sanner@medisin.uio.no</a></li> <li>• <a href="mailto:Sue.maillard@gosh.nhs.uk">Sue.maillard@gosh.nhs.uk</a></li> </ul>
	Telemedicine in JJIM	PReS / CARRA collaboration.	Ingrid Goh / Stacey Tarvin. PReS contact – Liza McCann <ul style="list-style-type: none"> <li>• <a href="mailto:Ingrid.goh@sickkids.ca">Ingrid.goh@sickkids.ca</a></li> <li>• <a href="mailto:starvin@iu.edu">starvin@iu.edu</a></li> <li>• <a href="mailto:Liza.mccann@alderhey.nhs.uk">Liza.mccann@alderhey.nhs.uk</a></li> </ul>
	Juvenile necrotizing myositis: an international cohort study	Open invite to contribute data to this international study.	Ilaria Maccora, <a href="mailto:ilaria.maccora@unifi.it">ilaria.maccora@unifi.it</a>

### Previous projects:

- Clinical care of calcinosis – Clarissa Pilkington / Charalampia Papadopoulou / Ovgu Kul Cinar.
  - Kul Cinar O, Papadopoulou C, Pilkington CA. Treatment of Calcinosis in Juvenile Dermatomyositis. *Curr Rheumatol Rep.* 2021 Feb 8;23(2):13. doi: 10.1007/s11926-020-00974-9. PMID: 33555459.
- Promoting education on use / interpretation of myositis antibodies. S. Tansley, Neil McHugh, Liza McCann, Raquel Campanilho-Marques. Resources included clinicians guide, Power Point presentation and podcast.
- Comparison and validation of skin tools in JDM - recent work by Brian Feldman and team. Previous work by Raquel Campanilho-Marques, Beverley Almeida.
  - Gebreamlak A, Sawicka KM, Garrett R, Goh YI, Baker KM, Feldman BM. Currently recommended skin scores correlate highly in the assessment of patients with Juvenile Dermatomyositis (JDM). *Pediatr Rheumatol Online J.* 2023 Jun 28;21(1):63. doi: 10.1186/s12969-023-00844-5. PMID: 37381026; PMCID: PMC10308717.
  - Campanilho-Marques R, Almeida B, Deakin C, Arnold K, Gallot N, de Iorio M, Nistala K, Pilkington CA, Wedderburn LR; Juvenile Dermatomyositis Research Group. Comparison of the Utility and Validity of Three Scoring Tools to Measure Skin Involvement in Patients With

- Juvenile Dermatomyositis. *Arthritis Care Res (Hoboken)*. 2016 Oct;68(10):1514-21. doi: 10.1002/acr.22867. Epub 2016 Sep 16. PMID: 26881696; PMCID: PMC5053292.
- Transition during Covid 19. Position Statement on PReS website under 'Clinical Affairs' then 'important papers'.
    - McDonagh JE, Tattersall R, Clinch J, Swan J, Foster HE, McCann LJ. Developmentally appropriate transitional care during the Covid-19 pandemic for young people with juvenile-onset rheumatic and musculoskeletal diseases: the rationale for a position statement. *Pediatr Rheumatol Online J*. 2021;19:136.PMID: 34433477.
  - Audit of implementation of SHARE guidelines & determination of current practice in Europe. Unpublished but used to inform further work. Summary available as appendix - Kul-Cinar et al.
  - Consensus Based Recommendations for the Management of Juvenile Dermatomyositis (SHARE recommendations) for diagnosis and treatment of JDM.
    - Bellutti Enders F, Bader-Meunier B, Baildam E, Constantin T, Dolezalova P, Feldman BM, Lahdenne P, Magnusson B, Nistala K, Ozen S, Pilkington C, Ravelli A, Russo R, Uziel Y, van Brussel M, van der Net J, Vastert S, Wedderburn LR, Wulffraat N, McCann LJ, van Royen-Kerkhof A. Consensus-based recommendations for the management of juvenile dermatomyositis. *Ann Rheum Dis*. 2017 Feb;76(2):329-340. doi: 10.1136/annrheumdis-2016-209247. Epub 2016 Aug 11. PMID: 27515057; PMCID: PMC5284351.
  - Criteria for Minimal, Moderate, and Major Clinical Response for Juvenile Dermatomyositis: An ACR/EULAR/IMACS/PRINTO Collaborative Initiative
    - Rider LG, Aggarwal R, Pistorio A, Bayat N, Erman B, Feldman BM, Huber AM, Cimaz R, Cuttica RJ, de Oliveira SK, Lindsley CB, Pilkington CA, Punaro M, Ravelli A, Reed AM, Rouster-Stevens K, van Royen-Kerkhof A, Dressler F, Magalhaes CS, Constantin T, Davidson JE, Magnusson B, Russo R, Villa L, Rinaldi M, Rockette H, Lachenbruch PA, Miller FW, Vencovsky J, Ruperto N; International Myositis Assessment and Clinical Studies Group and the Paediatric Rheumatology International Trials Organisation. 2016 American College of Rheumatology/European League Against Rheumatism Criteria for Minimal, Moderate, and Major Clinical Response in Juvenile Dermatomyositis: An International Myositis Assessment and Clinical Studies Group/Paediatric Rheumatology International Trials Organisation Collaborative Initiative. *Arthritis Rheumatol*. 2017 May;69(5):911-923. doi: 10.1002/art.40060. Epub 2017 Apr 6. Erratum in: *Arthritis Rheumatol*. 2018 Mar;70(3):467. PMID: 28382778; PMCID: PMC5577002.
  - Development of a consensus core dataset in JDM for clinical use to inform research. Collaborative initiative including members of PReS working party, PRINTO Centre Directors, and members of IMACS, CARRA, UK JDRG and patient/parent groups (Myositis UK and Cure JM).
    - McCann LJ, Pilkington CA, Huber AM, Ravelli A, Appelbe D, Kirkham JJ, Williamson PR, Aggarwal A, Christopher-Stine L, Constantin T, Feldman BM, Lundberg I, Maillard S, Mathiesen P, Murphy R, Pachman LM, Reed AM, Rider LG, van Royen-Kerkhof A, Russo R, Spinty S, Wedderburn LR, Beresford MW. Development of a consensus core dataset in juvenile dermatomyositis for clinical use to inform research. *Ann Rheum Dis*. 2018 Feb;77(2):241-250; PMID: 29084729
  - Collaboration with Euromyositis, including writing and promoting the use of JDM webpages for the Euromyositis registry. <https://euromyositis.eu/>.
    - Now MYONET: <https://www.myonet.info>
  - Sharing knowledge on projects relevant to all members including:
    - **The development of an internationally agreed biopsy scoring tool** - Varsani H, Charman SC, Li CK, Marie SK, Amato AA, Banwell B, Bove KE, Corse AM, Emslie-Smith AM, Jacques TS, Lundberg IE, Minetti C, Nennesmo I, Rushing EJ, Sallum AM, Sewry C, Pilkington CA, Holton JL, Wedderburn LR; UK Juvenile Dermatomyositis Research Group. Validation of a score tool for measurement of histological severity in juvenile dermatomyositis and association with clinical severity of disease. *Ann Rheum Dis*. 2015 Jan;74(1):204-10. doi: 10.1136/annrheumdis-2013-203396. Epub 2013 Sep 24. PMID: 24064003; PMCID: PMC4283618.
    - **An MRI-based scoring system in JDM** - Thyoka M, Adekunle O, Pilkington C, Walters S, Arthurs OJ, Humphries P, Johnson K, Kraft J, Landes C, Persaud T, Sinha R, Offiah AC. Introduction of a novel magnetic resonance imaging-based scoring system for assessing disease activity in children with juvenile dermatomyositis. *Rheumatology (Oxford)*. 2018 Sep 1;57(9):1661-1668. doi: 10.1093/rheumatology/key144. PMID: 29901756; PMCID: PMC6105921.

- **The JDM multidimensional assessment report, JDMAR** - Varnier GC, Ferrari C, Consolaro A, Marafon D, Pilkington C, Maillard S, Jelusic Drazic M, Dalpra' S, Civino A, Martini A, Ravelli A. PReS-FINAL-2012: Introducing a new approach to clinical care of juvenile dermatomyositis: the juvenile dermatomyositis multidimensional assessment report. *Pediatr Rheumatol Online J*. 2013 Dec 5;11(Suppl 2):P25. doi: 10.1186/1546-0096-11-S2-P25. PMID: PMC4044786.
- **Hybrid MMT-8/CMAS (hMC)**: Varnier GC, Rosina S, Ferrari C, et al. Development and Testing of a Hybrid Measure of Muscle Strength in Juvenile Dermatomyositis for Use in Routine Care. *Arthritis Care & Research*. 2018 Sep;70(9):1312-1319. DOI: 10.1002/acr.23491. PMID: 29245175.
- **The first composite disease activity score in JDM and definition of its cutoffs** – Rosina S, Consolaro A, van Dijkhuizen P, et al. Development and validation of a composite disease activity score for measurement of muscle and skin involvement in juvenile dermatomyositis. *Rheumatology (Oxford)*. 2019 Jul 1;58(7):1196-1205. doi: 10.1093/rheumatology/key421. PMID: 30690571; Rosina S, Consolaro A, Pistorio A, et al.; Paediatric Rheumatology International Trials Organisation (PRINTO). Defining criteria for disease activity states in juvenile dermatomyositis based on the Juvenile Dermatomyositis Activity Index. *RMD Open*. 2024 Feb 2;10(1):e003093. doi: 10.1136/rmdopen-2023-003093. PMID: 38307698; PMID: PMC10840041. PReS/ EULAR JDM module; part of the online course in Paediatric Rheumatology - Beverley Almeida, Liza McCann (previous author Lucy Wedderburn). <https://esor.eular.org>

## Appendix

### Pediatric Rheumatology European Society (PReS) Juvenile Dermatomyositis (JDM) Working Group survey of practice and use of SHARE recommendations.

Ovgu Kul Cinar, Meredyth Wilkinson, Raquel Campanilho-Marques, Helga Sanner, Judith Wienke, Saskia Veldcamp, Sara Röstland, Mette Nørgaard, Joanne Swan, Liza J McCann, Charalampia Papadopoulou, on behalf of the PReS JDM Working Group

#### Introduction:

The Single Hub and Access point for paediatric Rheumatology in Europe (SHARE) guideline for Juvenile Dermatomyositis (JDM) (1) was developed to provide unified and optimal access to care via evidence-informed consensus on diagnosis and treatment. To understand the implementation and impact in clinical practice, an online survey on the use of SHARE guideline (Survey 1) and a separate survey of current practice were written (Survey 2) (CH, LM) using Survey Monkey® and ratified by the JDM Working Party (WP) core group-

Both surveys were distributed to the members of the JDM WP (n=140) and PReS EMERGE (Paediatric Rheumatology European Society Emerging Rheumatologists and Researchers) group (n=150) between November 2019 to February 2020. Results were collated, and descriptive analyses were performed. Responses were anonymous (Table 1).

#### **Survey 1:**

Thirty-nine(85%) respondents reported SHARE guidance as important in their practice; 20(43.5%) stated important/incorporated into hospital/national guidelines, 16(34.8%) reported essential but not critical, and 3(6.5%) stated very important/essential for decision-making. Only 5(10.9%) reported not using SHARE guidance, and 2(4.3%) suggested they were of low importance. The majority, 41(89.1%), found SHARE recommendations clear, easy to use and valuable for education and training purposes. Almost half, 21(46.7%), suggested an update in the SHARE guideline, while 33(73.3%) found it relevant to their current practice as it is (Table 1). Although >60% of respondents stated that recommendations helped gain access to treatment/investigations, varied access to treatments 4(8.9%) and investigations 8(17.4%) was raised as an important obstacle, predominantly determined by each country's health system. A need for more specific information/guidance describing new biomarkers, myositis-specific (MSA) and myositis-associated antibodies, and their effects on clinical heterogeneity and outcomes was underlined (2). Nineteen(41.3%) participants acknowledged a need for additional recommendations, fundamentally involving newer therapies, novel biomarkers for disease activity and antibody measurement for risk stratification.

Further suggestions for additional items that respondents thought would be helpful to include in a revised SHARE recommendation included: 1) management of treatment-resistant/refractory disease, 2) treatment algorithms, 3) timing for treatment intensification, 4) addressing mental health issues during the disease course.

### Survey 2:

Survey 2 was designed with questions on current practice in idiopathic inflammatory myopathies (IIM) (Table 1). The majority (75.9%, n=25) thought that knowing the MSA subtype would influence their clinical practice. Ninety% (n=29) reported intravenous methylprednisolone as their induction steroid regimen in moderate-to-severe JDM. Methotrexate (MTX) was the most frequently preferred induction DMARD in moderate-to-severe JDM patients [84.9% (n=28)].

#### *Second-line treatment of severe skin disease with ulceration or lipodystrophy:*

The majority (36.4%, n=12) opted for intravenous immunoglobulin (IVIg), or cyclophosphamide (21.2%, n=7). Other favoured second-line options included: MMF (n=3), rituximab (n=3), TNF-inhibitors (n=2), ciclosporin(n=1), phosphodiesterase-4 inhibitor (sildenafil)(n=1), calcium channel blockers (n=1), and JAK-STAT inhibitors (n=1).

#### *Second-line treatment of severe muscle disease:*

Almost half of the group (45.4%, n=15) chose IVIg, followed by rituximab (12.1%, n=4), anti-TNF $\alpha$  (9%, n=3) and cyclophosphamide (9%, n=3). The use of MMF (n=2), ciclosporin (n=1) and rituximab as a third-line option after IVIg (n=2) were also reported.

#### *Second-line treatment for interstitial lung disease (ILD):*

Cyclophosphamide was the most frequently preferred agent (45.4%, n=15), followed by MMF (12.1%, n=4), rituximab (9%, n=3) and ciclosporin (6.1%, n=2). Three participants underlined that they would consider using JAK-STAT inhibitors in ILD, depending on the funding of the medication. Lack of experience treating ILD was reported by 3/33(9%), highlighting the importance of discussing those cases with tertiary/quaternary centres.

### Discussion:

In Survey 1, participants stated the need for structured algorithms in managing refractory JDM; nevertheless, evidence is lacking in this field to propose international consensus. Survey 2 reflected the current practice, yet was not evidence-based.

In view of the upregulated type I interferon signature in the pathogenesis, targeting components of this pathway with JAK-STAT inhibitors has been promising in JDM (3-6). However, clinical trials are needed for the safety and efficacy outcomes of these therapeutics (4). Head-to-head comparison studies and randomised clinical trials are required to gather robust evidence in the future. This may help overcome the uncertainty about therapeutic escalation options and create precise treatment algorithms.

Another important point raised in both surveys was the need for algorithms in regular mental health assessment. Establishing consensus-based recommendations that include psychosocial evaluations and health-related quality-of-life questionnaires is pertinent (7, 8).

Limitations of the surveys include the low response rate (16% of the total PReS JDM WP/EMERGE groups). Opinions and use of the SHARE guideline may differ among non-responders. Participants were not asked to comment on each item within the SHARE guideline, explicitly asking what needs to be updated at this stage because of developments in the field. Further work will include a more detailed survey which has recently been sent to IMACS/ PRES/ CARRA members asking to comment on each item of the SHARE survey.

In conclusion, the SHARE JDM recommendations have been widely implemented. The majority found it easy to use and helpful for their practice and decision-making. Nonetheless, nearly 50% reported that an update focusing on new biomarkers, myositis antibodies, novel treatment options (i.e. biologics, JAK-STAT inhibitors) and mental health assessment is warranted. Work is ongoing within a cross-party initiative (PReS, CARRA and IMACS) to update the SHARE guidelines for international use.

**Table 1.** Summary of survey results on 'practice in idiopathic inflammatory myopathies' and on the use of SHARE JDM guideline including respondents' opinions and experience

Survey on the use of SHARE JDM guideline (Survey 1)					
<b>Number of participants</b>	Paediatric Rheumatologists n (%)	Adult Rheumatologists n (%)	Paediatricians with Rheumatology interest n (%)	Internist n (%)	Parent representative n (%)
46	39 (84.8%)	3 (6.5%)	2 (4.4%)	1 (2.2%)	1 (2.2%)
<b>Experience in the specialty</b>	Consultant/academic/AHP ≥ 10 years n (%)	Consultant/academic/AHP 5-9 years n (%)	Consultant/academic/AHP <5 years n (%)	Trainee n (%)	Parent n (%)
	31 (67.4%)	9 (19.6%)	2 (4.4%)	3 (6.5%)	1 (2.2%)
<b>Main patient group</b>	Paediatrics n (%)	Adults n (%)	Combined (mainly paediatrics) n (%)	Combined (mainly adults) n (%)	
	40 (87%)	1 (2.2%)	3 (6.5%)	2 (4.3%)	
<b>Annual number of paediatric JDM/IIM patients</b>	30+ patients/year n (%)	20-29 patients/year n (%)	10-19 patients/year n (%)	5-9 patients/year n (%)	<5 patients/year n (%)
	11 (23.9%)	4 (8.7%)	11 (23.9%)	12 (26.1%)	8 (17.4%)
<b>SHARE Survey</b>	<b>Question</b>	<b>Yes n (%)</b>	<b>No n (%)</b>	<b>Unsure n (%)</b>	<b>Total n (%)</b>
<b>Opinion of SHARE guideline</b>	Clear & easy to use	41 (89.1)	1 (2.2)	4 (8.7)	46 (100)
	Useful for education & training	41 (89.1)	1 (2.2)	4 (8.7)	46 (100)
	Helps get the investigations I need for my patients	28 (60.8)	10 (21.7)	9 (19.6)	46 (100)
	Helps get the treatment I need for my patients	31 (67.4)	10 (21.7)	5 (10.9)	46 (100)
<b>Experience of SHARE guideline</b>	Contains investigations that I cannot access in my hospital	8 (17.4)	35 (76.0)	3 (6.5)	46 (100)
	Contains treatments that I cannot get in my hospital	4 (8.9)	36 (80)	5 (11.1)	45 (97.8)
	Needs to be revised & updated	21 (46.7)	16 (35.6)	8 (17.8)	45 (97.8)
	Relevant to my practice as it is	33 (73.3)	5 (11.1)	7 (5.6)	45 (97.8)
Survey of practice in idiopathic inflammatory myopathies (IIM) (Survey 2)					
<b>Number of participants</b>	Paediatric Rheumatologists n (%)	Adult Rheumatologists n (%)	Paediatricians with Rheumatology interest n (%)	Physiotherapist n (%)	Clinical academic/Researcher n (%)
34	30 (88.2%)	0	2 (5.9%)	1 (2.9%)	1 (2.9%)
<b>Experience in the specialty</b>	Consultant/academic/AHP ≥ 10 years n (%)	Consultant/academic/AHP 5-9 years n (%)	Consultant/academic/AHP <5 years n (%)	Trainee n (%)	Researcher n (%)
	19 (55.9%)	5 (14.7%)	7 (20.6%)	2 (5.9%)	1 (2.9%)
<b>Annual number of paediatric JDM/IIM patients</b>	30+ patients/year n (%)	20-29 patients/year n (%)	10-19 patients/year n (%)	5-9 patients/year n (%)	<5 patients/year n (%)
	6	2	15	5	5

	(18.2%)	(6.0%)	(45.4%)	(15.2%)	(15.2%)
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## References:

1. Bellutti Enders F, Bader-Meunier B, Baildam E, Constantin T, Dolezalova P, Feldman BM, et al. Consensus-based recommendations for the management of juvenile dermatomyositis. *Ann Rheum Dis*. 2017;76(2):329-40.
2. Tansley SL, McHugh NJ, Wedderburn LR. Adult and juvenile dermatomyositis: are the distinct clinical features explained by our current understanding of serological subgroups and pathogenic mechanisms? *Arthritis Res Ther*. 2013;15(2):211.
3. Papadopoulou C, Hong Y, Omoyinmi E, Brogan PA, Eleftheriou D. Janus kinase 1/2 inhibition with baricitinib in the treatment of juvenile dermatomyositis. *Brain*. 2019;142(3):e8.
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