

Supplementary Table 1. Summary of the studies included

Study (year) Country	Study design	n	AIM subsets	Age	Female n (%)	Disease duration (yrs)	Disease activity	Treatment	Pain measure (range)	Pain severity
Alexanderson et al. ¹ (1999) Sweden	Open label	10	DM, PM	Median (range) 53 (27-60)	8 (80)	Median (range) 4 (2-10)	Inactive disease on stable treatment	Baseline: GC 60%, AZA 50%, MTX 10%	SF-36 BP (0-100), VAS (0-100)	Baseline: SF-36 BP; median (range) 88 (25-100) VAS; median (range) 13 (0-75)
Alexanderson et al. (2000) ² Sweden	Open label	11	DM, PM, OM	Median (range) 47 (23-80)	8 (73)	Median (range) 0.2 (0.1-0.2)	Early AIM with less than 3 months of immunosuppression	Baseline: GC 100%, MTX 10% Oral steroids mg/day median (range): 40 (2.5-60)	SF-36 BP (0-100)	Baseline Median (range) 41 (0-84) 12 weeks Median (range) 72 (22-100)
Van der Meulen et al. ³ (2000) Netherlands	Cohort	8	DM, PM, NS	Mean ± SD 49 ± 16	7 (88)	<6 months	Newly diagnosed patients requiring treatment	Dexa 10 mg die for 4 days monthly for 3 months	VAS (0-10)	Mean ± SD Baseline: 4.5 ± 1.7 3 months: 2.5 ± 2
Chung et al. ⁴ (2001) UK	Cross-sectional	113	DM, PM	Mean (range) DM: 50 (25-75) PM: 54 (22-76)	113 (100)	Mean (range) DM: 7 (1-26) PM: 7 (1-25)	Acute cases excluded	N/A	NHP (0-100)	Mean ± SD All: 30 ± 32 DM: 30 ± 31 PM: 31 ± 33
Heikkilä et al. ⁵ (2001) Finland	Open label	22	DM, PM, IBM	Mean ± SD 55 ± 14	11 (50)	Mean ± SD 6.4 ± 6.1	68% stable medication for ≥ 3 months, 27% immunosuppression reduction in prior month	GC 91%, AZA 32%, MTX 14%, CYC 5%	VAS (0-100)	Mean ± SD 26 ± 27
Sultan et al. ⁶ (2002) UK	Cohort	34	DM, PM, OM, JDM	Mean 52	N/A	N/A	Active disease 21%	N/A	SF-36 BP (0-100)	Mean DM/PM: 55
Varjú et al. ⁷ (2003) Hungary	Cohort	21	DM, PM	Mean ± SD Early recovery: 51 ± 14 Chronic stage: 44 ± 15	16 (76)	Mean ± SD 3.8 ± 3.8	Early recovery: flare 2-3 weeks before study Chronic stage: stable for 3 months	AZA 24%, MTX 19%, CYC 24%	VAS (0-10)	Mean ± SD Baseline Early recovery: 34 ± 27 Chronic stage: 29 ± 24
Ponyi et al. ⁸ (2005) Hungary	Cross-sectional	87	DM, PM, OM	Mean ± SD 51 ± 11	67 (77)	Median (range) 8.9 (3-22.8)	Active disease 13%	GC alone (70%) On DMARD (30%)	SF-36 BP (0-100)	Mean ± SD DM: 54 ± 18 PM: 58 ± 20 OM: 66 ± 18

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Alexanderson et al. ⁹ (2007) Sweden	Open label	9	DM, PM	Median (range) 53 (44-61)	5 (56)	Median (range) 4.5 (2.7–29)	VAS 0–10; mean \pm SD Baseline: PhGA: 0.8 ± 1 PtGA: 2.8 ± 1.7 Post-training: PhGA: 0.8 ± 0.9 PtGA: 2.9 ± 1.5	Prednisolone mg/day median (range): 2.5 (0-7.5) AZA 67%, CsA 11%, MTX 11%	Borg scale (0-10)	Median (range) Baseline: 1.3 (0–3) Post-training: 1.3 (0–3)
Chung et al. ¹⁰ (2007) UK, Sweden	RCT	37	DM, PM	Mean Creatine: 59 Placebo: 50	31 (84)	Median [IQR] Creatine: 9.2 [1-52] Placebo: 8.6 [1-23]	Stable patients with low disease activity per inclusion criteria	Mean GC dose (mg/day): creatine 10.5 / placebo 7.5 AZA 22%, MTX 50%	NHP (0-100) SF-MPQ (0-78)	Mean \pm SD NHP Creatine: 38 ± 33 Placebo: 30 ± 29 SF-MPQ Creatine: 36 ± 27 Placebo: 25 ± 24
Sadjadi et al. ¹¹ (2010) UK	RCT	60	IBM	Mean \pm SD 65 ± 9	22 (37)	Mean \pm SD 4.4 ± 3	N/A	N/A	SF-36 BP (0-100)	Mean \pm SD IBM: 69 ± 27
van de Vlekkert et al. ¹² (2010) Netherlands	RCT	62	DM, OM, NS, NAM	Mean \pm SD Pred: 48 ± 13 Dexa: 49 ± 15	39 (63)	Median [IQR] Pred: 3.5 [1-11] Dexa: 4.5 [1-11]	Early AIM with active disease	Randomized to high dose prednisone vs dexamethasone in monotherapy	SF-36 BP (0-100) VAS (0-10)	Baseline VAS, median [IQR] Pred: 6 [3-10] Dexa: 6.5 [2-9] SF-36, median [IQR] Pred: 32 [0-100] Dexa: 32 [0-100] 18 months VAS, median [IQR] Pred: 4 [1-10] Dexa: 5.5 [3-8] SF-36, median [IQR] Pred: 72 [12-100] Dexa: 72 [0-100]
Goreshi et al. ¹³ (2011) USA	Cross-sectional	110	DM	N/A	N/A	N/A	CDASI (0-100): 19.5 ± 10.5	N/A	SF-36 BP norm-based VAS (0-100)	SF-36 BP, mean DM: 50 VAS, median 0.7

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Mahler et al. ¹⁴ (2011) Netherlands	Cohort	13	DM, PM	N/A	7 (54)	Median [IQR] 4 [2.5–6.5]	VAS 0–100; mean ± SD Baseline PhGA: 55 ± 8 PtGA: 49 ± 21	RTX 100% Median [IQR] GC dose (mg/day): 15 [11–20] Additional DMARDs N/A	VAS (0–100)	Mean ± SD Baseline: 21 ± 21 At 12 months: N/A
Regardt et al. ¹⁵ (2011) Sweden	Cross-sectional	31	DM, PM	Mean ± SD 56 ± 11	18 (58)	Mean ± SD 6.8 ± 5.5	N/A	GC 80%, Prednisolone mg/day; mean + SD: 6 ± 5 % on DMARD N/A	SF-36 BP (0–100)	Mean All: 58 DM: 55 PM: 58
Rose et al. ¹⁶ (2012) USA	Cross-sectional	43	DM, PM, IBM	Mean ± SD DM/PM: 56 ± 11 IBM: 63 ± 12	DM/PM: 13 (68) IBM: 6 (25)	N/A	N/A	N/A	INQOL	Mean ± SD PM/DM: 70 ± 19 IBM: 46 ± 29
Alexanderson et al. ¹⁷ (2014) Sweden	RCT	19	DM, PM	Median [IQR] 60 [52–67]	14 (74)	Median [range] 0.3 (0.2–0.3)	Early AIM (<3 months duration) improving on immunosuppression	Prednisolone mg/day median (range): 40 (30–60) AZA 68%, MTX 16%, CYC 11%	NHP (0–100)	Median [IQR] 9 [0–20]
Mattar et al. ¹⁸ (2014) Brazil	Open label	13	DM, PM	Mean ± SD 46 ± 9	9 (69)	Mean ± SD 5 ± 3	VAS 0–10; mean ± SD Baseline: PhGA: 2.6 ± 1.2 PtGA: 3.4 ± 1.4 12 weeks: PhGA: 1.2 ± 0.6 PtGA: 1.6 ± 1.2	GC 8%, AZA 54%, MTX 31%, MMF 8%	SF-36 BP (0–100)	Mean ± SD Baseline: 59 ± 11 12 weeks: 87 ± 15
van de Vlekkert et al. ¹⁹ (2014) Netherlands	Cohort	45	DM, OM, NS, NAM	Mean ± SD 49 ± 14	39 (63)	Median [§] Baseline: 0.3	At inclusion: early AIM with active disease At 18 months: in remission 33%, polyphasic 33% and chronic course 35%.	Baseline: See van de Vlekkert (2010). At 18 months: maintenance treatment in 68% (AZA, MTX, IVIg, MMF)	SF-36 BP (0–100)	Mean Baseline: 42 18 months: 70 Last follow-up*: 65
Cleary et al. ²⁰ (2015) USA	Cross-sectional	17	DM, PM, OM, IBM	Mean ± SD 56 ± 17	11 (65)	Median [IQR] 4 [2–13]	VAS 0–10; median [IQR] PhGA: 0.8 [0.7–4.5]	GC 59%, MTX 41%, HCQ 18%, AZA 12%, MMF 12%, RTX 12% Mean ± SD prednisone dose mg/day: 2.8 ± 1.3	SF-36 BP (0–100)	Median [IQR] 78 [45–95]

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Poulsen et al.²¹ (2017) Denmark	Case-control	75	DM, PM	Mean ± SD 60 ± 11	48 (64)	Median [IQR] 6.7 [4.1-13]	VAS 0–10; Median [IQR] PhGA 4.4 [2.2–6.7]	GC 21%, DMARD 20%, GC + DMARD 35%	SF-36 BP (0-100) VAS (0-10)	SF-36; mean ± SD 60 ± 26 VAS; median [IQR] 2.5 [0.7–4.8]
Feldon et al.²² (2017) USA	Cross-sectional	1806	DM, PM, IBM, adult JDM [†]	N/A	1262 (70)	Median [IQR] 9.2 [5–14]	N/A	N/A	SF-12 Norm-based	Mean + SE 43 ± 0.28
Tiffreau et al.²³ (2017) France	RCT	21	PM	Mean ± SD Program: 52 ± 10 Control: 58 ± 16	14 (67)	Mean ± SD Program: 3.8 ± 3.4 Control: 5.0 ± 6.4	Ongoing relapse Inclusion criteria included 20% decrease in muscle strength and myalgias	GC 100% Program: AZA 1% Control: MTX 27%	SF-36 BP (0-100), VAS (0-100)	SF-36, mean ± SD Program: 50 ± 25 Control: 48 ± 21 VAS, mean ± SD Program: 36 ± 37 Control: 29 ± 25
Alexanderson et al.²⁴ (2018) Sweden	Cohort	49	DM, PM	Mean ± SD 56 ± 14	31 (63)	Fixed visit 1 year after diagnosis	VAS 0–100; median [IQR] PhGA: 10 [4–24] PtGA: 27 [7–49]	Prednisolone mg/day [IQR]: 7.5 [5-12.5] On DMARD 94%	SF-36 BP (0-100)	Median [IQR] 74 [51–74]
Baschung-Pfister et al.²⁵ (2019) Germany	Cross-sectional	48	DM, PM, NS	Median [IQR] 60 [51-66]	36 (75)	Median [IQR] 1.5 [0.3-4.5]	Acute 19%, subacute 15%, chronic 67%	N/A	VAS (0-100)	Median [IQR] 14 [0-31]
Opinc et al.²⁶ (2019) Poland	Cross-sectional	377	DM, PM, OM, IBM [†]	N/A	256 (68)	<1 yr: 13% 1–5 yrs: 40% >5 yrs: 47%	N/A	N/A	VAS (0-100)	Mean ± SD DM: 37 ± 28 PM: 39 ± 29 OM: 38 ± 33 IBM: 22 ± 27
Wallace et al.²⁷ (2019) UK	Randomized single-blinded	17	IBM	Median (range) 62 (56-67)	4 (24)	N/A	6MWD (m); mean ± SD Group A: 327 ± 92 Group B: 270 ± 78	N/A	VAS (0-10)	Mean ± SD A-Baseline: 1 ± 2 B-Baseline: 1 + 3
Albrecht et al.²⁸ (2020) Germany	Prospective	1999: 170 2017: 72	DM, PM, OM	Mean ± SD 59 ± 14 [†]	113 (61) [†]	For 1997: <2 yrs: 30% 2-5 yrs: 29% >2 yrs: 41% For 2017: <2 yrs: 9% 2-5 yrs: 17% >5 yrs: 74%	For 1997: PhGA (0-3): 59% PhGA (4-6): 33% PhGA (7-10): 8% For 2017: PhGA (0-3): 94% PhGA (4-6): 6%	For 1997: GC 84%, AZA 39%, MTX 20%, CYC 7%, CsA 3% For 2017: GC 58%, AZA 26%, MTX 32%, CsA 7%, CYC 3%, MMF 8%, RTX 13%	NRS (0-10)	For 1999: Score 0-3: 47% Score 4-6: 34% Score 7-10: 19% For 2017: Score 0-3: 75% Score 4-6: 17% Score 7-10: 8%

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Christopher-Stine et al. ²⁹ (2020) USA	Cross-sectional	524 DM, PM†	Mean ± SD 55 ± 13	409 (78)	Mean ± SD 8 ± 7	In year prior: no flare 22%, 1-3 flares 47%, >4 flares 26%	GC only 7%, DMARD only 37%, GC + DMARD 43%	HAQ-pain (0-3)	Mean ± SD 1.04 (0.87)
Landon-Cardinal et al. ³⁰ (2020) France	Cohort	55 DM, IMNM, OM	Mean ± SD DM: 48 ± 17 IMNM: 54 ± 15 OM: 49 ± 15	DM: 10 (83) IMNM: 17 (63) OM: 14 (88)	Mean ± SD DM: 3 ± 2 IMNM: 9 ± 8 OM: 3 ± 4	DM VAS 0–10; mean ± SD PhGA: 3 ± 2 PtGA: 5 ± 2 IMNM PhGA: 2 ± 2 PtGA: 4 ± 3 OM PhGA: 3 ± 3 PtGA: 5 ± 12	GC 74%, MTX 26%, AZA 9%, MMF 15%, RTX 13%, IVIG 50%	SF-36 BP (0-100)	Mean ± SD All: 65 ± 26 DM: 55 ± 24 IMNM: 71 ± 24 OM: 63 ± 28 All (V2): 76 ± 21 All (V3): 73 ± 23
Rockette-Wagner et al. ³¹ (2021) USA	Cohort	50 DM, PM, IMNM, OM	Mean ± SD 52 ± 15	30 (60)	Mean ± SD 3.1 + 4.3	VAS 0–10; Mean ± SD 3.1 ± 2.3	N/A	VAS (0-10)	Mean ± SD 2.7 ± 2.6
Saygin et al. ³² (2021) USA	Cohort	50 DM, PM, IMNM, OM	Mean ± SD 52 ± 15	30 (60)	Mean ± SD 3 ± 4.2	VAS (0–10) Mean ± SD 3.1 ± 2.3	N/A	VAS (0-10)	Mean ± SD 2.7 ± 2.6
Xu et al. (2021) ³³ Australia	Cross-sectional	50 DM, PM, IBM, IMNM, NS	Mean ± SD 62 ± 13	29 (58)	Median [IQR] 5 [2.5–7.4]	VAS 0–100; median [IQR] PhGA: 17 [5–31] PtGA: 29 [11–49]	N/A	SF-36 BP (0-100)	Mean ± SD All: 63 ± 26 Gen pop: 77 ± 25

Legend: DM, dermatomyositis; PM, polymyositis; OM, overlap myositis; JDM, juvenile dermatomyositis; IBM, inclusion body myositis; NS, non-specific; NAM, necrotizing autoimmune myopathy; IMNM, immune-mediated necrotizing myopathy; PhGA, physician global assessment; PtGA, patient global assessment; CDASI, Cutaneous Dermatomyositis Disease Area and Severity Index; 6MWD, 6-minute walk distance; GC, glucocorticoid; AZA, azathioprine; CYC, cyclophosphamide; CsA, ciclosporin A; DMARD, disease-modifying antirheumatic drugs; MTX, methotrexate; MMF, mycophenolate mofetil; IVIG, intravenous immunoglobulins; RTX, rituximab; HCQ, hydroxychloroquine; Pred, prednisone; Dexa, dexamethasone; SF-36 BP, Short Form-36 Bodily Pain; VAS, visual analog scale; NHP, Nottingham Health Profile; INQOL, Individualized Neuromuscular Quality of Life Questionnaire; SF-12 Short Form-12; NRS, numerical rating scale; HAQ, Health Assessment Questionnaire; N/A, not available.

†On a subsample of 187 AIM patients assessed in 2015. ‡Self-reported.

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