

**Supplementary material**

Detailed description of the documented parameters in the registry for giant cell arteritis (GCA) and polymyalgia rheumatica (PMR) patients.

**Giant cell arteritis**

- demographics: date of birth, sex, weight, height
- disease characteristics: date of onset of symptoms, diagnosis date, level of diagnosis confidence;
- comorbidities: cardiovascular (stroke, transitory ischaemic attack, myocardial infarction, hypertension, venous thromboembolism); endocrine (diabetes, osteoporosis); infections; malignancy (haematological, skin, others).
- disease activity: patient global assessment, physician assessment (active, inactive, unknown)
- GCA-related specific symptoms;
- GCA-related clinical signs: temporal artery abnormalities, blood pressure left and right; detailed peripheral pulses (normal, weak, not present, not assessed) and vascular bruits (none, probable, definite) documented on a puppet;

- imaging (ultrasound, PET/CT, MRI) with exam date and detailed documentation of the involved arterial segments on a puppet.
- histology
- laboratory parameters: CRP, BSR, haemoglobin, leucocytes, thrombocytes, creatinine
- medication: current and previous to treat GCA; cardiovascular medications: aspirin, antihypertensive, statins; osteoporosis medications; analgesics; adverse events.
- quality of life reports: SF12 PCS (physical component score) and SF12 MCS (mental component score). This can be completed by the patient online. A reminder is sent to the patient automatically by SMS or email when a new visit is created in the database.

**Polymyalgia rheumatica**

- demographics: date of birth, sex, weight, height.
- disease characteristics: onset of symptoms, diagnosis date; PMR classification criteria at diagnosis: morning stiffness, bilateral shoulder pain, bilateral hip pain, neck pain,

ACPA (anticitrullinated protein antibody), rheumatoid factor, CRP or BSR elevated, shoulder and hip ultrasound.

- comorbidities: same as GCA.
- disease activity: patient global assessment (NRS), physician assessment (active, inactive, unknown).
- PMR-specific symptoms at visit: morning stiffness and duration, pain (if yes, with localisation on a puppet: shoulders, upper arms, neck, hips, upper leg, lower leg, lumbar), intensity of shoulder/ hip pain (NRS); peripheral arthritis (if yes with localisation).
- PMR- imaging: ultrasound, PET-CT, MRI. If conducted with exam date and documentation of the involved structures.
- histology of the temporal artery
- laboratory parameters (CRP, BSR, haemoglobin, leucocytes, thrombocytes, creatinine)
- biobanking (Serum and DNA)
- medication: current and previous to treat PMR; cardiovascular medications: aspirin, antihypertensive, statins; osteoporosis medications; analgesics; adverse events.

**Supplementary Table S1.** Specific PMR classification criteria at time point of diagnosis in the entire PMR cohort (n=99).

Variable	Frequency
Morning stiffness	76/82 (93%)
Shoulder girdle pain	83/87 (95.4%)
Pelvic girdle pain	74/86 (86%)
Neck pain	35/77 (45%)
Anti-CCP	
negative	62/79 (78.5%)
not tested	15/79 (19.0%)
positive	2/79 (2.5%)
Rheumatoid factor	
negative	62/77 (80.5%)
not tested	13/77 (16.9%)
positive	2/77 (2.6%)
ESR and/or CRP elevated	
no	1/81 (1.2%)
yes	80/81 (98.8%)
Sonography shoulder	36/73 (49%)
Sonography hip	16/71 (22.5%)

Anti-CCP: anti-cyclic citrullinated peptide antibodies.

**Supplementary Table S2.** Frequent co-medications in the entire GCA/PMR cohort\*.

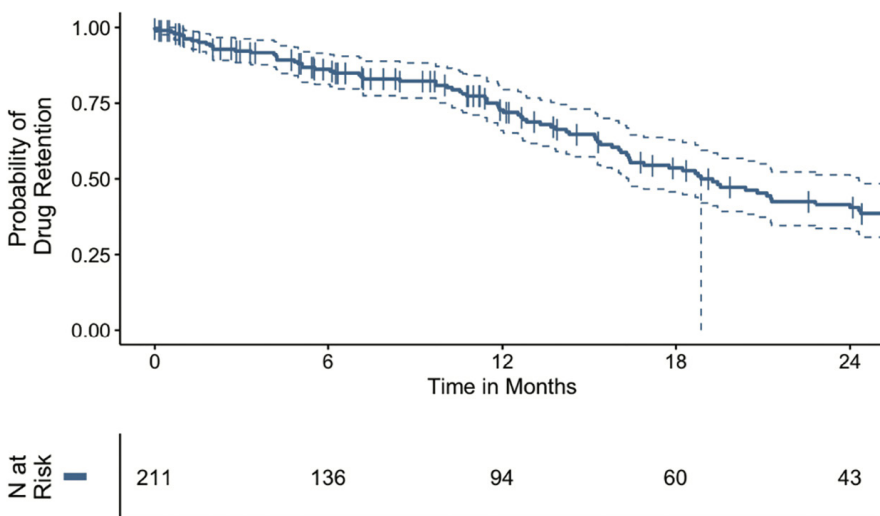
	GCA n=299, missing=38	PMR n=81, missing=17
<b>Osteoporosis</b>		
Calcium and/or vitamin D, n (%)	291 (97%)	69 (84%)
Bisphosphonates, n (%)	115 (39%)	10 (12%)
Teriparatide, n (%)	2 (1%)	1 (1%)
Denosumab, n (%)	12 (4%)	3 (4%)
<b>Cardiovascular</b>		
Platelet aggregation inhibitor, n (%)	151 (52%)	23 (28%)
Antihypertensives, n (%)	182 (62%)	40 (49%)
Statins, n (%)	116 (40%)	25 (31%)
<b>Others</b>		
Antidepressants, n (%)	37 (12.4%)	9 (11.1%)

\*ever reported throughout follow-up/inclusion visit.

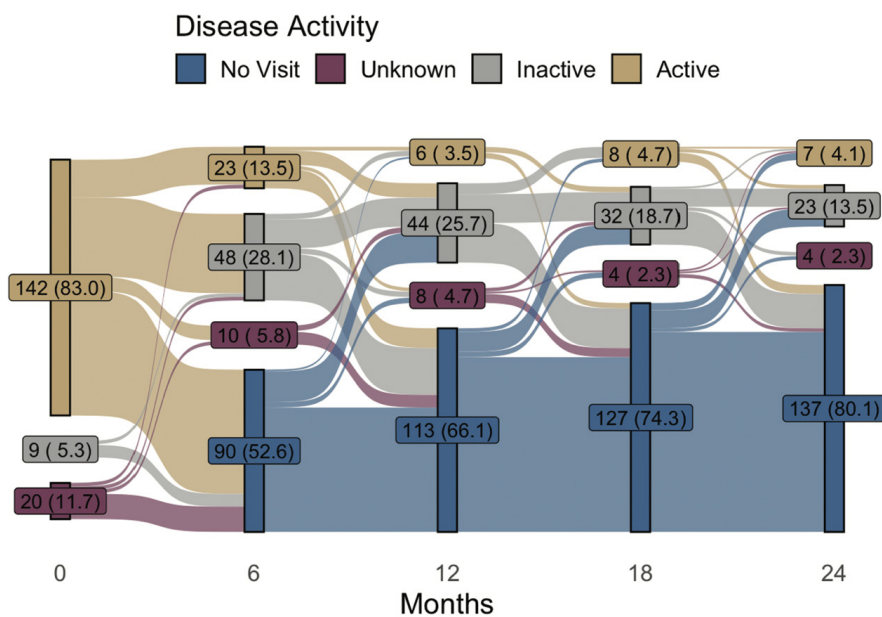
**Supplementary Table S3.** Reported infections (n=75) in GCA patients (n=337).

Infections	n=75
Abscess; n (%)	3
COVID; n (%)	12
COVID pneumonia; n (%)	2
Helicobacter pylori gastritis; n (%)	2
Diverticulitis; n (%)	2
Hepatitis B; n (%)	1
Oral candida; n (%)	1
Vaginal candida; n (%)	1
Pneumonia; n (%)	6
Pyelonephritis; n (%)	5
Skin/soft tissue infection; n (%)	3
Urinary tract infection; n (%)	6
Upper respiratory; n (%)	13
Herpes simplex skin; n (%)	1
Herpes simplex eye; n (%)	2
Infectious colitis	1
Others/not reported	14

COVID: coronavirus disease 2019.



**Supplementary Fig. S1.** Kaplan-Meier-curve of first tocilizumab treatment course in GCA patients, n=211.



**Supplementary Fig. S2.** Sankey-diagram of disease course in newly diagnosed GCA patients, n=171. Month 0 is diagnosis; active/inactive disease, statement of the physician by documenting the visit; unknown, explicit as “unknown” reported or when no visit in the last 18 months. For mapping a symmetric 3 months window is used (3 months before and after one visit).