First profiling of the national Swiss Clinical Quality Management giant cell arteritis and polymyalgia rheumatica registry

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Abstract

Objective

To describe patient characteristics, comorbidities, diagnostic approaches, and treatment patterns in the Swiss giant cell arteritis (GCA) and polymyalgia rheumatica (PMR) registry.

Methods

In 2020, a national GCA and PMR cohort was established within the Swiss Clinical Quality Management (SCQM) in rheumatic diseases registry.

Results

Between August 2020 and June 2024, 436 patients were included (337 GCA, 99 PMR). Median age was 72 years (IQR 65–77) in GCA and 71 years (IQR 63–77) in PMR; 64% and 56% were female, respectively. At diagnosis, 81% of GCA patients reported cranial symptoms, 31% visual symptoms, and 43% polymyalgic symptoms. In PMR, 95% reported shoulder girdle pain, 85% pelvic girdle pain, and 44% neck pain. Ultrasound was the most used diagnostic modality in GCA (76%), followed by PET-CT (59%) and MRI (40%). Temporal artery biopsy was performed in 29% of GCA patients, with a positivity rate of 66%. Glucocorticoids were still used by 79%, 50%, and 37% of GCA patients at 6, 12, and 24 months, respectively. Steroid-sparing agents were prescribed in 77% of patients, most commonly tocilizumab (73%). Common comorbidities included hypertension (51% GCA, 44% PMR), diabetes (15% GCA, 12% PMR), and osteoporosis (26% GCA, 15% PMR).

Conclusion

The SCQM registry provides real-world data on the management of GCA-PMR spectrum disease (GPSD) patients. Imaging has largely replaced histology for GCA diagnosis. Despite 75% of GCA patients receiving tocilizumab, one-third remained on glucocorticoids beyond 2 years. Such registries are expected to optimise care for this often fragile GPSD population.

Key words

giant cell arteritis, polymyalgia rheumatica, registry, ultrasound, tocilizumab

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Data availability: this study is based on data collected by the SCQM Foundation (Swiss Clinical Quality Management in Rheumatic Diseases), which operates a national registry for inflammatory rheumatic diseases. Access to the data is subject to restrictions and requires approval from the SCQM Foundation in accordance with the SCQM Rules of Research and Collaboration (https://www.scqm.ch/en/research/research-with-scqm-data/). Interested parties may contact the SCQM Foundation (research@scqm.ch) to request access to the data for research purposes.
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Introduction

Giant cell arteritis (GCA) and polymyalgia rheumatica (PMR) are closely related inflammatory rheumatic diseases of older adults, characterised by systemic inflammation (1), a predominant IL-6 signature, a good response to glucocorticoids, and a tendency to a chronic and relapsing course (2).

GCA is the most common vasculitis in adults, with a global incidence of 10 per 100,000 individuals aged over 50 years (3, 4). A north-south gradient has been described in the Northern Hemisphere, with the highest incidence reported in Scandinavia (21 per 100,000) (3). Women are affected two to three times more frequently than men (3).

PMR is the second most common inflammatory rheumatic disease after rheumatoid arthritis in Caucasians (5). Its geographical distribution is similar to that of GCA, with higher incidence rates in Northern Europe (33.6-113 per 100,000 aged >50 years) compared with Southern Europe (3.2-27.4 per 100,000) (6). Both diseases are rare in Asian populations. PMR is 3 to 10 times more common than GCA(6), and 40-60% of patients with GCA report concomitant PMR symptoms.

In patients with newly diagnosed PMR, vascular ultrasound revealed subclinical vascular involvement in 23% of cases (7) and a meta-analysis of patients with new-onset PMR undergoing PET-CT demonstrated a prevalence of subclinical vasculitis of 29% (8). These findings support the concept of GCA-PMR spectrum disease (GPSD) (2).

Systemic glucocorticoids (GCs) remain central to the treatment of GCA and PMR but are associated with substantial long-term toxicity, particularly given the frequently chronic and relapsing disease course. This contrasts with other inflammatory rheumatic diseases, for which several conventional or biological/small-molecule disease-modifying antirheumatic drugs (DMARDs) are well established. Tocilizumab (TCZ), an IL-6 receptor antagonist, was the only approved biologic therapy for GCA until 2025 and allows a more rapid 26-week glucocorticoid taper (9). However, the optimal duration of therapy remains unclear, as discontinuation of tocilizumab has been associated with a considerable risk of disease flare (10-13).

For patients with PMR and a chronic or relapsing course, approved steroid-sparing treatment options are also limited. Sarilumab, another IL-6 receptor antagonist, has been approved for refractory PMR by the U.S. Food and Drug Administration (FDA) since March 2023 and the European Medicines Agency (EMA) since October 2024; however, sarilumab is not approved for PMR in Switzerland.

Systematically collected data on disease manifestations, treatment, comorbidities, and outcomes parameters (*e.g.* relapse and sustained remission) in GCA and PMR remain scarce. The 2018 EULAR recommendations for a core dataset to support observational research and clinical care in GCA emphasise the need for registries to systematically collect real-world data, facilitate international collaboration, and enable larger datasets. Such data are essential to improve and standardise care and to identify prognostic factors (14). Several countries have established national GCA registries, including the United Kingdom GCA consortium, the GeVas Vasculitis Registry in German-speaking countries (15), ARTESER in Spain (16), and Reuma.pt/vasculitis in Portugal (17). Newly combined GCA/PMR registries, such as DANIVAS in Denmark (18) and initiatives in Italy, are also being developed.

In this context, a national registry for patients with PMR and/or GCA was implemented in 2020 within the Swiss Clinical Quality Management in Rheumatic Diseases (SCQM) foundation. SCQM collaborates closely with the Swiss Society of Rheumatology (SGR) and operates established national registries for several inflammatory rheumatic diseases, including rheumatoid arthritis, axial spondyloarthritis, and psoriatic arthritis (19). Within the registry, biobanking has been established. (https://www.scqm.ch).

This manuscript presents the first profiling of the SCQM GCA/PMR registry. The aims are to describe: i) patient characteristics, comorbidities, diagnostic findings, and treatment patterns; ii) the

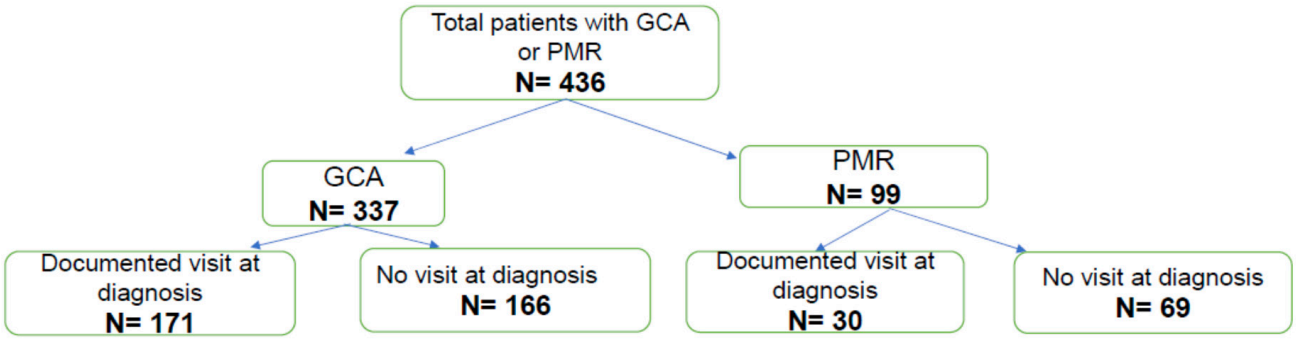

Fig. 1. Flow chart of the patient registry.
A documented visit at diagnosis was defined as a visit recorded in the registry within 14 days of diagnosis.
GCA: giant cell arteritis; N: number of patients; PMR: polymyalgia rheumatica.

geographical distribution of patients; iii) selected aspects of registry functionality.

Methods

Patients

Criteria for inclusion in the SCQM GCA/PMR registry are a new or established diagnosis of GCA or PMR according to the treating rheumatologist and written informed consent for participation. For biobanking, a separate written informed consent is required.

SCQM GCA/PMR registry

In August 2020, we initiated a longitudinal registry for patients diagnosed with GCA and/or PMR within the SCQM Foundation. Data entry is performed by the treating rheumatologist/immunologist using a web-based, two-factor-secured electronic care report form. Rheumatologists across Switzerland, from academic and non-academic institutions as well as private practices, have access to the registry to document patient data. Data may be entered in German, French, or Italian, the primary official languages of Switzerland.

Patients are ideally followed at 3-month intervals after diagnosis during the first year and thereafter at 6-month intervals. Relapses are expected to be documented, followed by 3-monthly visits for one year.

The dataset is based on the 2018 EULAR recommendations for a core set of parameters in GCA registries (14). Demographics, disease characteristics, comorbidities, detailed imaging results, laboratory results and medications are documented (detailed item description in the Supplementary material).

For PMR patients, data on demographics, disease characteristics, pain, imaging, laboratory results, and medications are documented (detailed item description in the Supplementary material). In addition, fulfilment of the 2012 provisional PMR classification criteria (20) at the time of diagnosis is recorded. Comorbidities and cardiovascular risk factors are documented without information on the date of onset.

Ethics

The study was approved by the Ethics Committee of Northwest and Central Switzerland (EKNZ), project ID 2023-02365. All patients provided written informed consent for participation in the SCQM registry.

Definitions and statistical analysis

Due to the registry-based design, not all variables were available for all patients. Therefore, denominators vary across analyses (*e.g.* imaging modalities, comorbidities) and are reported explicitly for each analysis. No imputation of missing data was performed.

A visit at diagnosis was defined as a visit documented within 14 days of diagnosis. For the analysis of diagnostic imaging, available modalities (ultrasound, PET-CT, MRI) performed within the first two months after diagnosis were analysed.

Cardiovascular (CV) risk factors were defined as a categorical variable comprising smoking, diabetes and/or hypertension and ranged from 0 to 3 (0=no CV risk factor; 1=one CV risk factor; etc).

A patient was considered to have cranial symptoms if any of the following symptoms were present: headache, scalp tenderness, jaw claudication, painful or indurated temporal arteries and/or ocular symptoms. Ocular symptoms included blurred vision, diplopia, and/or transient or permanent vision loss.

An infection at diagnosis was defined as an infection reported within 14 days before or after the GCA diagnosis.

P-values for comparisons of patient characteristics were derived using Fisher's exact test for nominal variables and the Kruskal-Wallis test for continuous variables. Retention of glucocorticoid therapy was estimated using the Kaplan-Meier method. All statistical analyses were performed using the R statistical software (21).

Results

Demographics

From its inception in August 2020 until 1 June 2024, a total of 436 patients were included in the registry: 337 with GCA and 99 with PMR (Fig. 1).

In the GCA cohort, 51% (171/337) of patients were newly diagnosed (defined as diagnosis ≤14 days before registry inclusion), whereas 30% (30/99) of patients with PMR were newly diagnosed at the time of registry inclusion. The remaining patients were included cross-sectionally after diagnosis; therefore, baseline characteristics at diagnosis were unavailable for a proportion of patients.

Overall, 1450 visits were recorded for the 436 patients. Geographically, nearly half of the patients were included in the Basel region (217/436; 49.8%), followed by Bern (81/436; 18.6%), Geneva and Zürich (each 38/436; 8.7%),

and Saint Gallen (27/436; 6.2%). Other regions accounted for 35/436 (8%) patients (Fig. 2).

Most patients (321/436, 74%) were enrolled at university hospitals, while 55/436 (12%) were included at regional hospitals and 60/436 (14%) at private rheumatology practices.

The median age at diagnosis of the GCA patients was 72 years [IQR 65-77; range: 50-97], of the PMR patients 71 years [IQR 64-77; range: 50-93]. The proportion of female patients was slightly higher in GCA than in PMR (64% *vs*. 57%).

The median duration of symptoms prior to diagnosis was shorter in GCA than in PMR (40 vs. 52 days, respectively).

Active smoking was reported by 19% of GCA patients compared with 2.6% of PMR patients (p=0.001). PMR patients had a higher median body mass index (BMI) than GCA patients (25.6 *vs*. 23.9 kg/m^2; p=0.02).

GCA patients had a higher prevalence of ischemic stroke at the first registry visit compared with PMR patients (7.1% [21/295] *vs*. 1.1% [1/91]; p=0.035) (Table I). In GCA patients, strokes occurred at a median time of 38 days (IQR 2.5, 748) after GCA diagnosis.

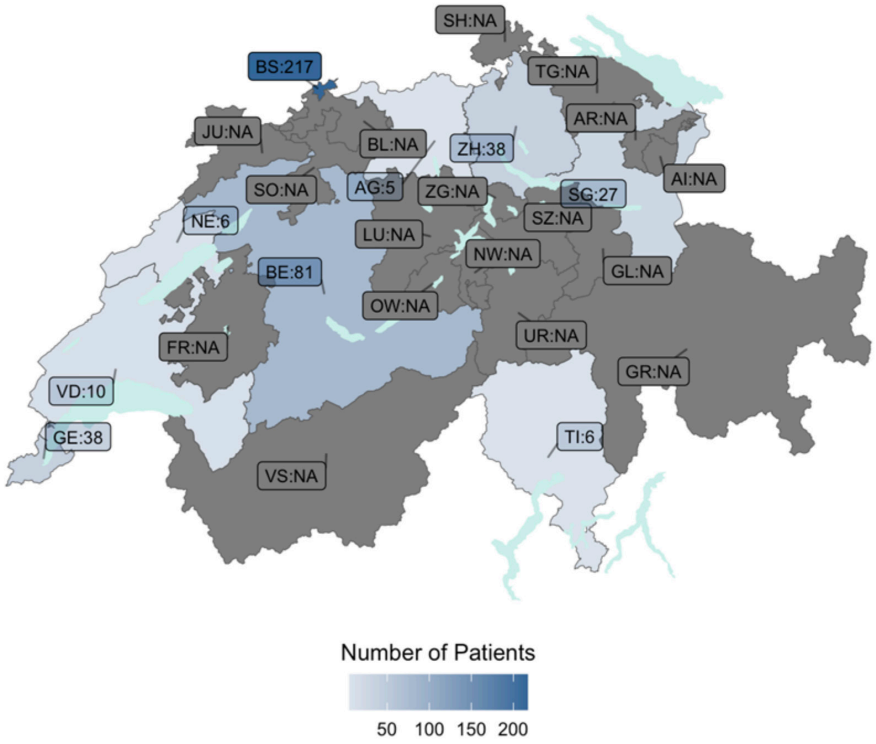

Fig. 2. Geographical distribution of registry patients by Swiss canton*.
Map of Switzerland showing the patient distribution across the 26 Swiss cantons.
*Patients were assigned to the canton of their first documented registry visit. Most patients were included in Basel (BS) (217/436; 49.8%), followed by Bern (BE) (81/436; 18.6%), Geneva (GE), Zürich (ZH) and St. Gallen (SG). Cantons with fewer than 5 patients were coded as NA to preserve anonymity. Canton abbreviations indicate official Swiss two-letter codes.

Comorbidities documented at the first visit

Due to missing data, denominators varied across comorbidity analyses. Hypertension was documented in approximately half of the GCA patients (137/269; 50.9%) and in 43.7% (38/87) of the PMR patients. Diabetes was present in 14.5% (39/269) of GCA patients and in 11.5% (10/87) of PMR patients. A history of venous thromboembolism (VTE) was reported in 6.4% of GCA (17/264) patients compared to 3.6% of PMR patients (3/83).

Osteoporosis was more frequently documented in GCA patients, with a prevalence of 26.2% (67/256), compared with 15.2% (12/79) in PMR patients.

Among GCA patients, 2.1% (6/292) had a history of haematological malignancy, including one case each of chronic lymphocytic leukaemia (CLL), chronic myelomonocytic leukaemia (CMML), myelodysplastic syndrome (MDS), follicular non-Hodgkin lymphoma, as well as 2 cases of monoclonal gammopathy of undetermined significance (MGUS).

Characteristics of PMR patients at diagnosis

At diagnosis, 95% of PMR patients reported shoulder girdle pain, 86% pelvic girdle pain, and 93% morning stiffness.

An elevated erythrocyte sedimentation rate (ESR) and/or C-reactive protein (CRP) level was documented in 99% of patients (Supplementary Table S1).

Most patients tested negative for rheumatoid factor (RF) (81%) and anti-cyclic citrullinated peptide (anti-CCP) antibodies (78.5%). However, anti-CCP status was not documented in 19% of the patients and RF status in 17%. Anti-CCP antibodies were detected in 2.5% (2/79) and RF in 2.6% (2/77) of patients. No patients were double-positive for RF and anti-CCP antibodies.

At the inclusion visit, the physician's degree of diagnostic confidence in PMR was reported as strong in 59% of cases (47/80), whereas in the remaining 41% (33/80) the diagnosis was considered suspected.

A documented visit at diagnosis was available for 30/99 (30%) PMR patients. These patients reported a median global disease activity of 6/10 on visual analogue scale (VAS) and a median duration of morning stiffness of 2 hours [IQR 1–3].

Across all visits, 12/99 (12%) PMR patients presented peripheral arthritis, involving the wrist (3/12), knee (3/12), metacarpophalangeal (MCP) joints (4/12), proximal interphalangeal (PIP) joints of the hands (3/12) and elbows (2/12).

Characteristics of GCA patients at diagnosis

Of the total of 337 GCA patients in the registry, 171 (51%) were included at diagnosis. Again, due to missing data, denominators varied across the analyses. Cranial symptoms were present in 81% (124/153) of the patients, with new onset headache being the most common cranial symptom, reported

Table I. Demographics and comorbidities of GCA and PMR patients, as documented by the first cohort visit.

Variable	Level	GCA (n=337)	PMR (n=99)	Available n (GCA/PMR)	*p*-value
Patients newly diagnosed		171 (51%)	30 (30%)		
Demographics					
Sex, n (%)	female	217 (64.4)	56 (56.6)	337/99	0.159
Age at diagnosis (years)	median [IQR-range; min, max]	72 [65-77; 50, 97]	71 [63-77; 49, 87]	318/87	0.177
BMI, kg/m^2	median [IQR]	23.9 [21.8, 27.1]	25.6 [23.0, 29.5]	176/56	0.02
Time from symptoms to diagnosis, days	median [IQR]	40 [14, 96]	52 [25, 123]	271/85	0.04
Comorbidities					
Smoking, n (%)	Current	43 (19.1)	2 (2.6)	225/77	0.001
	Past	53 (23.6)	21 (27.3)		
Osteoporosis n (%)		67 (26.2)	12 (15.2)	256/79	0.049
Hypertension n (%)		137 (50.9)	38 (43.7)	269/87	0.268
Diabetes n (%)		39 (14.5)	10 (11.5)	269/87	0.592
Number of cardiovascular risk factors, n (%)	0	58 (27.4)	33 (43.4)	212/76	0.047
	1	92 (43.4)	27 (35.5)		
	2	51 (24.1)	11 (14.5)		
	3	11 (5.2)	5 (6.6)		
Myocardial infarction n (%)		11 (3.8)	3 (3.3)	291/90	1.0
TIA n (%)		5 (1.7)	2 (2.2)	289/91	0.675
TIA: days from diagnosis	Median [IQR]	4 [0, 322]	4692 [2909, 6474]		
Ischaemic stroke, n (%)		21 (7.1)	1 (1.1)	295/91	0.035
Ischaemic stroke: days from diagnosis	Median [IQR]	38 [2.5, 748]	8256 [8256, 8256]		0.098
VTE n (%)		17 (6.4)	3 (3.6)	264/83	0.427
Malignancies					
Skin, n (%)		5 (1.7)	3 (3.6)	291/83	0.385
Haematological, n (%)		6 (2)	0 (0.0)	291/84	0.207
Other malignancy, n (%)		35 (12)	7 (8.4)	292/83	0.549

Percentages are calculated based on available data. Due to missing values, denominators vary across variables.
CV risk factors: smoking, diabetes and/or hypertension.
BMI: body mass index; IQR: interquartile range; TIA: transient ischaemic attack; VTE: venous thromboembolism.

by 58% (92/159) of patients. The median reported headache intensity on the visual analogue scale (VAS) was 6/10 (IQR 4-8) (Table II).

Visual symptoms were reported by 31% (48/156) of patients, with blurred vision being the most frequent (14%, 22/156), followed by diplopia (10%). Unilateral visual loss was present in 8% (12/156) of patients, whereas 3% (4/156) presented with bilateral visual loss (Table II). Among these 171 newly diagnosed GCA patients, 26 (15%) had a previous diagnosis of PMR, which evolved into GCA after a median of 124 days [IQR 6, 765].

Imaging and histology at diagnosis in GCA patients

For 193 out of 337 GCA patients, information on the diagnostic imaging modalities used for diagnosis was available. The majority of patients, 76% (147/193) underwent vascular ultrasound, followed by PET-CT in 59% (114/193) and

Table II. Disease features of the newly diagnosed GCA patients, n=171.

Variable	Frequency reported/available n (%)
Cranial symptoms including ocular	124/153 (81%)
Headache	92/159 (57.9%)
Headache VAS (0-10) (median [IQR])	6.00 [4.00, 8.00]
Scalp tenderness	45/138 (32.6%)
Jaw claudication	57/149 (38.3%)
Painful or indurated temporal arteries	41/137 (29.9%)
Ocular involvement	48/156 (30.8%)
Diplopia	16/156 (10.3%)
Blurred vision	22/156 (14.1%)
Vision loss unilateral	12/156 (7.7%)
Vision loss bilateral	4/156 (2.6%)
General symptoms	
Night sweats	47/141 (33.3%)
Fever	24/143 (16.8%)
Weight loss	75/147 (51%)
Polymyalgic symptoms (%)	39/91 (42.9%)
Laboratory parameters	**Median** [IQR]
ESR, mm/h	58 [30, 87]
CRP, mg/l	55 [19, 109]

Percentages are calculated based on available data. Due to missing values, denominators vary across variables.
ESR: erythrocyte sedimentation rate; CRP: C-reactive protein; VAS: visual analogue scale; anti-CCP: anti-cyclic citrullinated peptide antibodies; n: number of patients with available information.

Table III. Frequency and results of diagnostic methods used to confirm GCA (imaging/histology).

Diagnostic method	GCA patients n (%)	Results of vasculitis diagnostic method n (%)		
Total	193	positive	possible	negative
Ultrasound † (%)	147 (76.2%)	94 (64%)	16 (11%)	37 (25%)
MRI (%)	77 (40%)	51 (66%)	6 (8%)	20 (26%)
PET-CT (%)	114 (59%)	83 (73%)	13 (11%)	18 (16%)
Ultrasound + PET-CT	78/193 (40%)			
Ultrasound + MRI	63/193 (33%)			
PET-CT + MRI	22/193 (11%)			
Ultrasound + PET-CT + MRI	18/193 (9%)			
Total	**337**			
Histology of the temporal artery	97 (29%)	64 (66%)	8 (8%)	25 (26%)

*for 193 out of 337 GCA patients information on the diagnostic imaging modality used within the first 2 months after diagnosis was available.
†ultrasound, vascular ultrasound.
MRI: magnetic resonance imaging; cranial and/or thoracic and extracranial supra-aortal arteries; PET-CT: positron emission tomography.

MRI in 40% (77/193) of cases. Most patients (85%) underwent more than one imaging modality (Table III).
In the entire GCA cohort, 29% (97/337) of patients underwent temporal artery biopsy (TAB). Among these, 66% (64/97) fulfilled histological criteria for giant cell arteritis, 8% (8/97) were reported as suspicious for GCA, and 26% (25/97) were negative.

Imaging in the PMR cohort
Among the PMR patients, 16 of 99 (16.2%) underwent PET-CT during the documented follow-up period. The most frequently reported abnormalities included increased FDG uptake around the shoulders (8/11 patients), hips (9/11), spinous processes (5/9), and ischial tuberosities (4/10). All of these patients remained classified as PMR after PET-CT. It was not possible to assess how many PMR patients were reclassified as GCA following imaging. In addition, the original dataset of the registry did not capture whether PMR patients underwent vascular ultrasound for GCA screening. The most frequently used imaging modality in PMR was ultrasound of the shoulders and hips: a total of 110 ultrasound examinations were performed across 197 documented visits.

Treatment

Duration of glucocorticoid treatment in newly diagnosed GCA patients
Glucocorticoid treatment data were available for 152 of the 171 newly diagnosed GCA patients. At 6 months after diagnosis, 79% (116/147) of patients remained on oral glucocorticoids, 50% (70/140) at 12 months and, 37% of patients were still receiving glucocorticoids at 24 months. The median daily dose was 8.75 mg prednisone-equivalent at 6 months and 5 mg at 12 months. The median duration of glucocorticoid treatment was 377 days (95% CI: 338–420). A Kaplan-Meier curve illustrating glucocorticoid retention is shown in Figure 3.

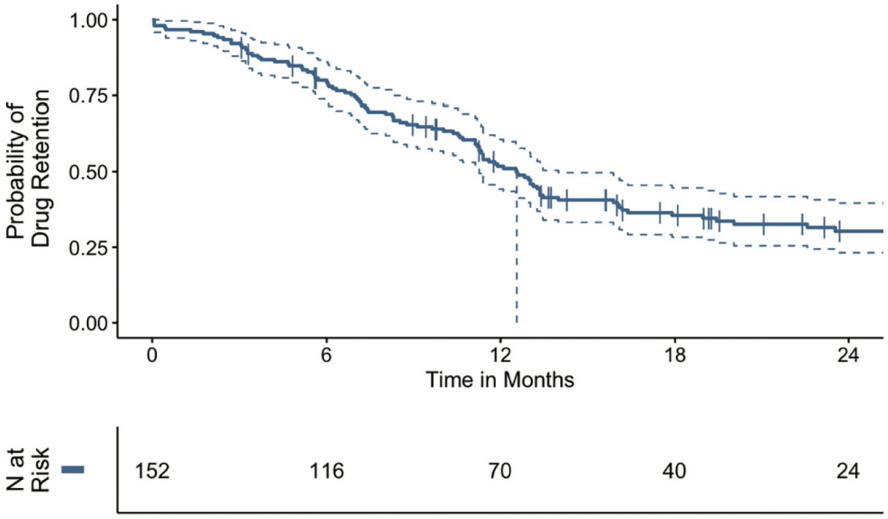

Fig. 3. Kaplan-Meier curve showing glucocorticoid retention over 24 months in newly diagnosed giant cell arteritis (GCA) patients (n=152).
Dashed lines indicate 95% confidence intervals; tick marks represent censored observations.

Use of disease modifying anti-rheumatic drugs (DMARDs) in the entire GCA/PMR registry
During the documented follow up, 23% (69/337) of the GCA patients did not receive any steroid-sparing therapy. The majority of GCA patients were treated with tocilizumab (73%; 220/300), followed by methotrexate (14%; 42/300). Abatacept was prescribed in 5% (16/300), leflunomide in 1.7% (5/300), and cyclophosphamide in 1.3% (4/300) of patients.
Overall, 11% (33/300) of GCA patients received two different steroid-sparing therapies (tocilizumab, methotrexate, or abatacept) during follow-up, and 2.5% (7/300) were treated with all three at any time point.
In the PMR cohort, 30% (27/91) of patients received steroid-sparing therapy with methotrexate, 15% (14/91) were treated with tocilizumab, and 3% received leflunomide. In total, 9% (8/91) of PMR patients received both methotrexate and tocilizumab at any time point during follow-up.

Tocilizumab retention in GCA patients
The median time from GCA diagnosis to initiation of tocilizumab (TCZ) was

87 days (IQR: 31–247) and the median TCZ retention time during the first treatment course was 18.6 months (95% CI: 16.1–24.0 months) (Suppl. Fig. S1).
Among tocilizumab-treated GCA patients, 17% (35/211) had two treatment courses, with TCZ reinitiated after prior discontinuation; 4% (9/211) received three treatment courses, and 2% (5/211) received four courses during follow-up.

Concomitant medications
Cardiovascular medications were commonly used in the overall GCA/PMR registry. Antihypertensive therapy was prescribed in 62% of GCA and 49% of PMR patients; platelet aggregation inhibitors in 52% and 28%, respectively; and statins in 40% and 31%, respectively.
Osteoporosis-specific therapies were more frequently prescribed in GCA than in PMR patients, especially bisphosphonates (39% *vs*. 12%). Use of denosumab and teriparatide was similar in both groups (4% *vs*. 1%, respectively) (Suppl. Table S2).

Longitudinal follow-up
The 171 newly diagnosed GCA patients had a total of 652 documented visits, with a median follow-up interval of 84 days (IQR: 42, 179). The 30 newly diagnosed PMR patients had 39 follow-up visits overall, with a median interval of 119 days (IQR: 78, 215) between visits. Across the entire PMR cohort, patients had a mean of 2 documented visits. At baseline, 83% (142/171) of the GCA patients had active disease. Half of these patients had no documented follow-up visit at 6 months (Suppl. Fig. S2).

Infections
In the entire GCA cohort (337 patients), 66 infections were reported during follow-up. Infections occurred at a median of 646 days (IQR: 136, 1304) after GCA diagnosis. Nine infections were reported at diagnosis, defined as occurring within 14 days before or after the GCA diagnosis.
The most frequently reported infections were upper respiratory tract infections (13/75), COVID-19 (12/75), pneumonia (8/75), urinary tract infections (6/75), and pyelonephritis (5/75). A detailed description of infection types is provided in Supplementary Table S3. Overall, 22% of GCA patients experienced at least one infection at diagnosis or during follow-up. No infections were documented during follow-up in the PMR cohort.

Discussion

This study presents the first comprehensive description of the Swiss SCQM GCA/PMR registry from its inception in August 2020 through June 2024. A total of 337 patients with GCA and 99 with PMR were enrolled, predominantly from tertiary rheumatology centres across Switzerland. Recruitment was geographically clustered in Basel, Bern, Geneva, Zurich, and St Gallen. Rheumatology offices contributed 14% of the patients.
The age and sex distributions of PMR and GCA patients were as expected and comparable to those reported in other cohorts. GCA patients were more likely to be current smokers than PMR patients, a known risk factor for GCA (22), and tended to be slightly younger (median age 72 years) than patients in the German GeVas registry (76 years) (15), though overall age at diagnosis and sex ratios were comparable to other large GCA cohorts (17, 23). PMR demographics likewise mirrored those reported in a major U.S. series (24) and a Finnish university hospital cohort (25).
Cranial symptoms were reported in 81% of GCA patients in our registry, comparable to the 78% and 80% reported in German (15) and Spanish (23) registries, respectively. Ocular symptoms were present in 30% of our patients *versus* 31% and 37% in the German and Spanish registries, respectively. Permanent vision loss (PVL) was observed in 10% of patients, comparable to findings from other multicentre registries but lower than in single-centre cohorts, where incidences of 14–19% have been reported (26-28). Whether this discrepancy reflects selection bias or underdiagnosis remains uncertain.
The median symptom-to-diagnosis interval for GCA was 40 days, slightly longer than the 32 days reported by a Dutch fast-track clinic (29), but shorter than delays observed in other international series: 2.9 months (23) and 63 days (30). Diagnostic delay, particularly between symptom onset and referral to rheumatology or a fast-track clinic remains a key contributor to permanent vision loss in GCA (26).
In more than one third of PMR cases, significant diagnostic uncertainty was noted, reflecting the intrinsic diagnostic challenges of PMR due to its nonspecific clinical presentation. Previous studies have shown that the diagnosis of PMR may be revised in up to one third of patients during follow-up (31-33).
In our registry, 12% of PMR patients presented with peripheral arthritis at inclusion or during follow-up. Higher frequencies (25–31%) have been reported in previous studies (34, 35), likely reflecting longer follow-up periods of 5 and 12 years, respectively, during which cumulative incidence was assessed.
Diagnostic delays were longer in PMR (median 52 days) than in GCA (median 40 days). A Danish PMR fast-track clinic reduced this delay to 53 days compared with 80 days historically. Nevertheless, the nonspecific clinical presentation and early glucocorticoid use may still complicate timely diagnosis (33). The importance of reducing diagnostic delay in PMR has recently been highlighted in international recommendations (36).
Among the 171 newly diagnosed GCA patients, 15% had a prior diagnosis of PMR and were reclassified as GCA after a median of 124 days. This observation supports the concept of a GCA-PMR spectrum disease (GPSD) and may reflect either subclinical vasculitis at PMR onset or disease evolution over time (2). Screening of PMR patients at diagnosis for subclinical vasculitis has only emerged over the past two years. In our registry, 16% of the PMR patients underwent a PET-CT, and remained classified as PMR.
GCA diagnosis was most frequently confirmed by imaging. Vascular ultrasound was performed in 76% of patients, followed by PET-CT (59%) and MRI (40%). Temporal artery biopsy (TAB) was conducted in a minority of patients (29%). This diagnostic approach aligns with current EULAR

recommendations, which prioritise imaging- particularly ultrasound, and reserve biopsy for selected cases (37).

Despite widespread use of steroid-sparing therapies, glucocorticoid exposure remained substantial. At 12 months, 50% of GCA patients were still receiving glucocorticoids (GCs), and at 24 months, 37% continued GC treatment, underscoring the chronic nature of the disease. Only 23% of GCA patients did not receive any steroid-sparing therapy. The higher proportion of patients remaining on GCs at one year in the GeVas registry (77%) may reflect differences in disease severity and treatment strategies. In particular, cyclophosphamide was used more frequently (16%) and tocilizumab less frequently (48%) than in our registry (1.3% and 73%, respectively). Regulatory differences in access to tocilizumab may also contribute.

Nevertheless, the proportion of GCA patients receiving glucocorticoids beyond one year has declined over time (23, 38-40). In a Danish cohort spanning 1996 to 2018, 64%, 40%, and 34% of patients remained on glucocorticoids at 2, 5 and 10 years, respectively (41).

Comorbidities at baseline were common in both groups: hypertension (51% GCA *vs*. 44% PMR), diabetes (15% GCA *vs*. 12% PMR), myocardial infarction (3.8% GCA *vs*. 3.3% PMR), and osteoporosis (26% GCA *vs*. 15% in PMR). These frequencies were largely comparable to other cohorts (15), although hypertension (65%) and diabetes (21%) were more prevalent in the Spanish ARTESER cohort (23), while osteoporosis was less frequently reported in the German GeVas GCA cohort (9%).

Ischaemic stroke occurred in 7% of GCA patients and clustered early after diagnosis, with a median of 38 days. This rate is consistent with published literature reporting stroke frequencies between 3% and 7% (23, 38-40). The risk of stroke in GCA is approximately 1.4-fold higher than in age- and sex-matched controls (42). In the DCVAS cohort, the world's largest vasculitis cohort, the incidence of stroke at GCA diagnosis was 2.3% (43). The higher rate of stroke observed among GCA patients in our registry is likely explained by inclusion of patients with established disease and cumulative event capture, as only half of patients were newly diagnosed at inclusion.

Infections were documented in 22% of GCA patients over a median follow-up of 646 days. This proportion may underestimate the true infection burden due to incomplete follow-up, with only 50% of patients having a documented visit at 6 months. In comparison, a Danish cohort reported antibiotic-treated infections in 52.4% of patients within the first year after GCA diagnosis (44).

A major limitation of the registry is the low number of PMR patients. Although PMR is 3–10 times more prevalent than GCA, our registry included three times more GCA than PMR cases, likely reflecting the low referral rates of PMR patients to specialist care in Switzerland, especially to tertiary centres. International data suggest that only about 25% of PMR patients are referred to rheumatologists (45). This may limit the generalisability of the PMR-related findings, as the included patients could represent a more selected, difficult-to-treat PMR population. Efforts to improve PMR registry recruitment are ongoing, including outreach at national society meetings, email invitations, and updates to primary care physicians on current EULAR recommendations for the management of PMR patients, which emphasise rheumatology referral. The development of PMR fast-track clinics may further help improve specialist access.

Another important limitation is that the original 2019 registry dataset did not capture whether PMR patients underwent vascular ultrasound for GCA screening. We are planning a dataset refinement to address this gap.

Additional limitations include incomplete documentation of serological testing in PMR patients, with anti-CCP and RF status missing in 19% and 17%, respectively. These tests are recommended in the 2012 EULAR/ACR classification criteria for PMR and were likely not performed or not updated in the registry. Incomplete follow-up also remains a challenge, with only 50% and 33% of GCA patients having documented visits at 6 and 12 months, respectively. This reflects the difficulty of integrating comprehensive research documentation into routine clinical care.

In conclusion, this first profiling of the Swiss GCA/PMR registry confirms epidemiological and clinical patterns reported in other cohorts. GCA and PMR are chronic diseases associated with substantial comorbidity and persistent diagnostic delays. Although this manuscript is primarily descriptive, the registry is designed to support future analyses on imaging and clinical outcomes, such as relapse frequency and long-term damage accrual. The SCQM registry provides a valuable platform for future research into the GPSD spectrum and the real-world effectiveness of novel steroid-sparing therapies, with the aim of improving patient outcomes.

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Competing interests

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