Attending and non-attending patients in a real-life setting of an early arthritis clinic: why do people leave clinics and where do they go?

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Abstract

Objectives

Rheumatologist assessment as early as possible is considered essential for patients with inflammatory joint disease. In our Very Early Arthritis Clinic (VEAC), a substantial proportion of initially included and followed patients later stop attendance in the clinic. We questioned attending (AP) and non-attending patients (NAP) regarding current health status and satisfaction with care as well as reasons for discontinuation and current care received by NAP.

Methods

VEAC patients first seen between 1996 and 2003 were included. Assessment included the RADAI, HAQ, and visual analogue scales for pain, disease activity, fatigue, satisfaction with current health care. Current (DMARD) treatment was recorded.

Results

Among AP, 87% had rheumatoid arthritis (RA) and 13% non-RA. Of NAP, 37% had RA, 23% non-RA and 40% no more rheumatic disease. Satisfaction with health care concerning rheumatic disease was better in AP than NAP. Likewise, most outcome parameters were better in AP. Substantially more RA patients in the AP than NAP group received DMARDs. Apart from the disappearance of arthritis, logistic reasons were given most frequently for discontinuation of attendance. Less than 10% of NAP indicated dissatisfaction with medical care.

Conclusions

We found advantages in both disease activity measures and satisfaction with health care for patients receiving continuous care in a highly specialised Rheumatology clinic. Furthermore, different DMARD usage in RA in AP and NAP may indicate significant deficits in treatment quality outside specialist care. Logistic issues associated with access to continuous Rheumatology care for early arthritis patients need improvement.

Key words

very early arthritis, attending patients, non-attending patients, patient satisfaction

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Introduction

Rheumatoid arthritis (RA) is a chronic disabling disease, characterised by synovial inflammation, cartilage and bone destruction. The inflammatory process may be persistent and may lead to permanent joint damage, physical disability, loss of quality of life and socio-economic consequences (1-5). Interventions in RA include drug treatment with synthetic and biological disease modifying antirheumatic drugs (DMARDs), glucocorticoids, non-steroidal anti-inflammatory drugs (NSAIDs) as well as physical and occupational therapy and psychological approaches (6, 7). Notably, therapeutic interventions tend to become less effective if started later in the course of the disease because joint destruction is regarded to be essentially irreversible and thus cumulative (8-11). Early intervention in RA has been found to reduce long-term joint damage, physical disability and loss of quality of life (12, 13). Considering that clinical presentation can initially be non-specific with the frequent difficulty to discriminate between severe courses and more benign forms (14), initial assessment by a rheumatologist as early as possible is thought to be essential (15). To achieve this goal of early specialist assessment, dedicated "early arthritis clinics" have been established during the past two decades.

Whereas follow-up by a rheumatology specialist does not appear mandatory for patients with self-limiting disease such as viral arthritis or other benign, non-destructive arthritides, it can be considered essential for patients with destructive arthritis such as RA (16-18).

There is no single definition of "early arthritis", therefore both disease duration and additional criteria (such as number of joints involved or laboratory criteria) in patients with "early arthritis" (EA) vary and patients with a few months to 5 years symptoms duration were included in different early (rheumatoid) arthritis cohorts (19-25). The Austrian Very Early Arthritis Cohort (VEAC) set the upper limit for inclusion in the very early arthritis cohort at 12 weeks from symptom onset (26, 27).

After initial care in the Austrian VEAC-Clinics in a framework of a social system with open access to medical care, a sizable proportion of patients discontinue to be followed regularly in the clinic. This can easily be explained by the fact that only patients with symptom duration of less than 3 months are included in the VEAC, and self-limiting disease (*e.g.* reactive arthritis) is seen in the flare but eases off soon making it unattractive, and, in fact, unnecessary for the patient to attend clinics as soon as symptoms have disappeared.

Nevertheless, reasons for patients to discontinue attendance in the Austrian VEAC-clinics remained speculative to date and there may be several factors influencing patients' decisions. The results of our study could point out possibilities for improvement to responsible physicians in everyday patient care.

The aims of this study were (I) to assess the current health status of patients who stopped to attend the EA-Clinic (non-attending patients, NAP) compared to patients who still attend regularly (attending patients, AP), (II) to assess satisfaction with care in both NAP and AP, (III) to investigate reasons for discontinuation of attendance, and (IV) to investigate current care received/required by NAP.

Methods

Austria's social system allows patients free choice of physician and/or institution, either clinics or offices, the latter either private or in contract with social insurances. Ideally, patients report with their first symptoms to their general practitioner, who, in the case of arthritis of any kind, should then refer the patient to a specialist in rheumatology. Rheumatologists' assessment and treatment is largely clinic-based with only very few rheumatologists available in private practice. The Medical University of Vienna is the biggest University hospital in Austria and accommodates one of the largest rheumatologic outpatient clinics. In 1996, the Very Early Arthritis Clinic (VEAC) was initiated, an ongoing cohort study providing rapid access to rheumatology care and collecting data on all very early arthritis patients seen in our specialised clinics.

Patients

The VEAC includes patients with inflammatory arthritis of ≤12 weeks du-

ration. Inflammatory arthritis is defined as non-traumatic pain or swelling of at least one joint plus laboratory signs of an inflammatory response (elevated erythrocyte sedimentation rate [ESR], elevated C-reactive protein [CRP], or positive rheumatoid factor [RF]) (9, 26, 27). Routinely, follow-up visits in the VEAC are scheduled at 3-monthly intervals for patients with active disease. In case of low disease activity or remission, visits are usually lengthened to a maximum of 6 months.

Patients were considered eligible for the present study if they fulfilled the following criteria:

1. inclusion in the VEAC (from 1996 to 2003),
2. first visit and follow-up visits at the Medical University Hospital of Vienna,
3. follow-up at the clinic for at least 3 months.

Patient recruitment for this survey was done over a period of 8 months from May to December 2005. Patients who were willing to participate had to give written informed consent according to the Declaration of Helsinki (most recently at the General Assembly in October 2008). The study was approved by the Ethics Committee of the Vienna Medical University.

Assessment in detail

Attending patients (AP) in the VEAC received a set of questionnaires. Patients who had initially been followed up for ≥3 months but had failed to attend the clinic for at least 6 months were defined as non-attending patients (NAP) and received the same questionnaires by mail with a prepaid return envelope.

The set of questionnaires included the Rheumatoid Arthritis Disease Activity Index (RADAI) (28) and the Stanford Health Assessment Questionnaire (HAQ) as measure of functional disability in a validated German version (29, 30). Patients' pain, disease activity, fatigue and satisfaction with current health care were assessed using separate visual analogue scales (VAS, from 0 to 100mm) for pain, disease activity, and fatigue, 0 denoted "least", 100 "maximum"; for satisfaction, in contrast, 0 denoted "maximally", and 100 "least" satisfied. In addition, patients were asked to complete a questionnaire regarding their socio-economic status (educational level, employment status, monthly income) and current usage of health services (physicians, physiotherapists, occupational therapists, nursing, pharmacists). All patients were asked to give their final diagnosis (last diagnosis given by their last treating physician), which was then compared to their diagnosis on record.

Non-attending patients were finally asked to state reasons for them to discontinue attendance out of a list of possible answers: no symptoms, no medication, no disease anymore, or one of the following: time to travel to the clinic, length of wait in clinics, change of personnel (doctor rotation) in the clinic, impersonal care, dissatisfaction with care. In addition, an open question about the reasons for discontinuation of the attendance of the VEAC was posed and the results qualitatively analysed: "Please try to describe the reasons why you are not attending the Rheumatology Ouptpatient Clinic of the Medical University of Vienna anymore".

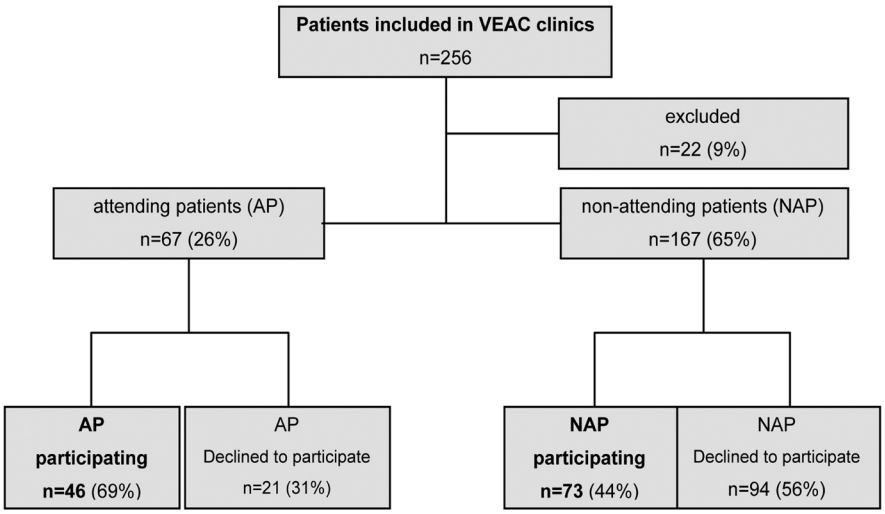

Fig. 1. Very Early Arthritis Cohort between 1996–2003. 256 patients were included in the VEAC during this period. 22 failed to attend clinics for ≥3months. 67 attending patients (AP) were still regularly seen in clinics between May and December 2005. 167 non-attending patients (NAP) were contacted by mail or by phone and asked to participate.

Statistical analysis

Due to the exploratory nature of this study, mainly descriptive statistics and frequency analyses were applied.

Comparisons between AP and NAP were performed applying Chi-squared test for nonparametric comparisons and Mann-Whitney U-test (for non-normally distributed variables) or *t*-test (for normally distributed variables) for continuous data.

Analyses were performed with the SPSS statistical software, version 15.0.

Results

Participation

Two hundred and fifty-six patients were included in the VEAC. Of these, 22 patients were only seen once or attended clinics for less than 3 months and were therefore excluded from the present analysis. Thus, 234 patients were contacted for this study: 67 qualified as AP and were contacted in person at their scheduled visit. NAP were contacted for this study by telephone and/or by mail (n=167). Figure 1 demonstrates the recruitment process: participation among AP was 69%, among NAP 44%. Asked informally, patients who declined to participate in the AP and NAP, the latter being contacted by telephone, declared mainly personal reasons, and few patients reported restrictions on language understanding, as reasons for declining to participate.

Patients' characteristics

Patients' characteristics are shown in Table I. AP and NAP did not differ significantly in any of the demographic characteristics. Patients who did not return the questionnaires did not differ

from participants in terms of age or gender (data not shown). Detailed analysis of possible consequences of disease on professional status revealed the following: only one patient in the AP and none in the NAP declared to work only part time as a consequence of disease; of the unemployed patients, 100% in the AP and 50% in the NAP group stated that their unemployment was related to the disease. 14% of the retired AP and 8% of the retired NAP said that retirement was due to the disease.

Diagnoses in AP and NAP

Table II shows diagnoses in AP and NAP: in the NAP group (n=73) 40% were healthy (patients stated to have no more rheumatologic symptoms and no treatment), 37% were diagnosed as RA and 23% as non-RA. Among AP 87% had RA and only 13% non-RA.

Disease activity and outcome measures in attending and non-attending RA and non-RA patients

Significant differences between RA patients still attending clinics (RA-AP) and RA patients who were non-attenders (RA-NAP) were found in their satisfaction with health care providers (Table III-A): RA-AP were significantly more satisfied (VAS median 7 mm) with their care providers compared to RA-NAP, who had left care in clinics (VAS median 19 mm; p=0.028). The other significant finding relates to fatigue: RA-AP again were significantly better (VAS median 23 mm) compared to RA-NAP (VAS median 53 mm; p=0.005). Albeit not reaching statistical significance, all parameters except the HAQ showed better values for RA-AP compared to RA-NAP.

In Table III-B the same parameters of disease activity (except RADAI, which is not validated in non-RA) are shown for non-RA patients still attending clinics (nRA-AP), and non-RA patients cared for outside clinics (nRA-NAP). Again, the VAS on satisfaction with health personnel is significantly better in nRA-AP (VAS median 7) compared to nRA-NAP (VAS median 30; p=0.001). All other parameters showed a clear trend towards better values for nRA-AP, but were not statistically significant.

Table I. Characteristics of attending patients (AP) and non-attending patients (NAP). There was no statistically significant difference in age, gender, disease duration, educational level, and place of living or professional status between the two groups.

	AP (n=46)	NAP (n=73)
Age years, median (IQR)	58 (47.75; 68)	55 (39; 64.5)
Gender (%)		
Female	70	66
Male	30	34
Disease duration months, median (IQR)	60 (48; 96)	60 (36; 84)
Educational level (%)		
University degree	22	25
High School degree	28	23
Apprenticeship	26	32
Compulsory school	22	13
Unknown	2	7
Place of living (%)		
Big city	67	71
Small city or village	33	29
Professional status (%)		
Employed	39	48
Unemployed	7	6
Retired	46	36
Household	8	10

p=n.s. for all items.

Table II. Diagnoses of AP and NAP.

	AP (n=46)	NAP (n=73)
Healthy = no symptoms, no medication	–	29 (40%)
RA	40 (87%)	27 (37%)
Non-RA	6 (13%)	17 (23%)
Reactive arthritis	1	2
Degenerative arthropathy	1	5
Connective tissue disease	3	–
Psoriatic arthritis	–	1
Undifferentiated arthritis	–	6
Polymyalgia rheumatica	1	–
Inflammatory bowel disease	–	1
Gout	–	2

Treatment in RA-AP and RA-NAP

In RA patients, NSAIDs (45% *vs*. 44%; p=n.s.) and glucocorticoids (25% *vs*. 29.6%; p=n.s.) were prescribed equally frequently in attenders and non-attenders.

Of 40 RA-AP, 30 patients received synthetic only and 4 biological DMARDs (3 of these in combination with a synthetic DMARD). In RA-NAP (n=27), 13 were treated with synthetic and 3 with biologic DMARDs (2 in combination with a synthetic DMARD).

Altogether 85% RA-AP and 60% RA NAP were treated with synthetic and/or biological DMARDs (p=0.0774). Of the 6 AP not being treated with DMARDs despite being diagnosed with RA, 4 were in remission, in 1 patient DMARDs were paused while he was introduced to dialysis due to end-stage renal disease (with fatal outcome during the year following this investigation), and 1 patient became pregnant and stopped all medication including DMARDs except low-dose glucocorticoids. Reasons for not receiving DMARDs are not known, but to exclude remission in RA-NAP in these patients, VAS disease activity was compared between those NAP receiving synthetic and/or biological DMARDs and those not receiving any DMARD, with numerically higher VAS disease activity in those without current DMARD therapy (mean 38.5 *vs*. 29.0; p=n.s).

Table III. Outcome parameters and disease activity in AP and NAP.
A. RA patients. Attending RA patients (RA-AP) showed statistically significantly higher satisfaction with health personnel and less fatigue than RA patients not attending clinics anymore (RA-NAP).

Median (IQR)	RA-AP (n=40)	RA-NAP (n=27)	*p*-value
VAS satisfaction health care provider*	7 (1; 21)	19 (7; 38)	0.028
VAS pain**	20 (3; 41)	26 (7; 41)	0.549
VAS disease activity**	22 (2; 46)	37 (14; 49)	0.215
VAS fatigue**	23 (7; 51)	53 (40; 67)	0.005
HAQ**	0.4 (0.0; 1.0)	0.3 (0.0; 0.4)	0.073
RADAI**	1.6 (0.9; 3.8)	2.5 (1.9; 3.6)	0.311

B. Non-RA patients. Attending non-RA patients (nRA-AP) showed statistically significantly higher satisfaction with health personnel than patients not attending clinics anymore (nRA-NAP).

Median (IQR)	nRA-AP (n=6)	nRA-NAP (n=17)	*p*-value
VAS satisfaction health care provider*	7 (2; 7)	30 (16; 39)	0.001
VAS pain**	3 (2; 27)	31 (8; 42)	0.238
VAS disease activity**	8 (4; 21)	28 (8; 48)	0.294
VAS fatigue**	6 (3; 33)	51 (14; 70)	0.055
HAQ**	0.1 (0.0; 0.1)	0.1 (0.0; 0.6)	0.204

VAS, visual analogue scale; HAQ, health assessment questionnaire; RADAI, rheumatoid arthritis disease activity index. Values were non-normally distributed, therefore medians and interquartile ranges are given.
*higher values denote less satisfaction; **higher values denote worse outcome.

Table IV. Non-attending patients (NAP) – where do they go? 7% of RA patients who chose to leave regular care in clinics are not seen by any physician, and another 26% by a physician who is not a trained rheumatologist. Of non-RA (nRA) patients who left clinics, only 12% still see a rheumatologist for their rheumatic condition.

	RA (n=27)	nRA (n=17)	n. of symptoms (n=29)
Other rheumatology clinic	14 (52%)	2 (12%)	0
Rheumatologist in private practice	4 (15%)	0	0
Other physician	7 (26%)*	7 (41%)**	2 (7%)***
No rheumatologic care	2 (7%)	8 (47%)	27 (93%)

*of the 7 RA patients not seeing a rheumatologist, but another physician, 6 see their General Practitioner and "1 another physician"; **of the 7 nRA patients in this category, 5 see their General Practitioner and 2 "another physician" because of their rheumatic condition; ***2 patients in the healthy group still are in follow-up with "another physician" because of their former rheumatic condition.

Treatment in nRA-AP and nRA-NAP

Among nRA-AP (n=6), 3 received synthetic DMARDs and all 3 were diagnosed with connective tissue disease. Of nRA-NAP (n=17), again 3 received synthetic DMARDs: diagnosis was degenerative arthropathy (presumably activated), inflammatory bowel disease and psoriatic arthritis.

Reasons for discontinuation

NAP (n=73) were asked to indicate among multiple choices their reasons for discontinuation. The reasons in the order of frequency were: no rheumatologic symptoms (33%), long length of wait in the clinic (11%), change of personnel (doctor rotation) in the clinic (10%), time to travel to the clinic (7%), impersonal care (6%), dissatisfaction with care (3%) and other causes (14%). Thus, aside from "no rheumatologic symptoms", the most frequent reasons for discontinuation the clinic were related to administrative and logistic issues. Only 9% were unsatisfied with the received care (stating general dissatisfaction or "impersonal" approach to care by the physicians).

An open question about reasons for discontinuation the attendance was also analysed qualitatively: it was possible to identify 4 relevant conceptual categories: necessity to return to the clinic (patients and physician's viewpoint), administration aspects, relationship between patient and physician and disagreement between patient and physician. The necessity to return to the VEAC-Clinic was the most frequent category described. Most of these patients emphasised the absence of rheumatologic symptoms as the main cause for interrupting care. Secondly, patients mentioned administrative aspects as a reason for discontinuation the VEAC-Clinic. These administrative issues were represented by: change of personnel (doctor rotation), long length of wait in the clinic, long time interval between appointments, time spent by patients to reach the clinic and changing residence to another city/country. While altogether not well represented, an interrelationship between the last two categories was observed, affecting directly the relationship between patient and rheumatologist through disagreement: disagreement was related to treatment (change of medication, side effects), use of alternative medicine and distinction between joint disease and "whole body".

Where did NAP go?

Table IV demonstrates that 14 (52%) of RA-NAP (n=27 total) indicated to be treated in other outpatient rheumatology clinics, and 4 (15%) stated to be in the care at a rheumatologists` private office. Six (22%) were cared for by a general practitioner and one patient was cared for by "another physician" for his RA. Two patients did not see any physician. This implies that 33% of NAP with RA were not seen regularly by a rheumatologist.

Of nRA-NAP (n=17 total), only 2 (12%) were still in rheumatological follow-up, 5 (29%) saw their GP regularly and 2 saw other physicians because of their rheumatologic conditions, leaving 8 patients with no follow-up with any physician.

Of healthy NAP (n=29), 27 (93%) did not see any physician because of their former rheumatic condition, as they were symptom-free and took no medication for this former disorder. Only 2 patients were still in the care of a non-rheumatologist.

Discussion

After initial care in the VEAC for several months (or years), a sizeable proportion of patients decided not to return to clinics. We compared those patients still attending clinics (attending patients, AP) with those not attending clinics anymore (non-attending patients, NAP), using a detailed questionnaire in both groups.

Disease activity measures at the time of the survey showed that nearly all parameters assessed, both in the RA and in the non-RA group, were clearly better in attending patients. Remarkably, attending patients were significantly more satisfied with their current care (in the framework of the VEAC) as compared to non-attending patients (who had left the framework of the VEAC). This was true for all patients, both RA and non-RA. In addition, RA patients still attending clinics demonstrated significantly less fatigue compared to those who had left. All other parameters except the HAQ were numerically (although not statistically significantly) better in attending patients.

It is considered mandatory for patients with RA to be treated with a synthetic and/or biological DMARD, as only these can halt disease progress (31, 32). In RA patients attending clinics, 85% received DMARDs at the time of this investigation. Of the 6 patients without DMARD, 2 had a contra-indication and 4 were in clinical remission. Of those RA patients who chose to discontinue care in our clinics, only 60% received DMARDs. This difference in percentages of DMARD-treated RA patients between the attending and non-attending group may indicate significant deficits in treatment quality outside specialised care.

Since patients seen in clinics do better in terms of disease activity, receive more DMARDs, show significantly less fatigue and are significantly more satisfied with their care than those who had left clinics, the question arises: why did they go and not return? On analysis of the reasons for discontinuation we found that the most frequent reasons, in symptomatic patients, were of administrative or logistic nature: patients complained about long waiting times in clinics, doctors` rotations with changing physicians in charge, and the burden of long travel times to clinic. Only a very small proportion stated that their reason for discontinuation was the lack of satisfaction with the received care.

Last of all, where did NAP go? Our results show that 40% of NAP reported to be healthy; in these healthy "former-patients", non-attendance was the logical consequence. In contrast, for a non-RA patient, follow-up with a rheumatologist may or may not be appropriate, depending on the actual diagnosis given: in our NAP cohort, 53% had degenerative arthropathy, reactive arthritis or gout, all of which might either be self-limiting or benign. Diagnosis of the other 47%, namely undifferentiated arthritis, psoriatic arthritis and arthritis associated with inflammatory bowel disease, were altogether diagnoses which would most likely benefit and should be cared for by a trained rheumatologist. Especially for patients with RA, though, it is an established and proven advantage to persistently see a rheumatologist (16-18, 33). Most remarkable was therefore the finding that 33% of RA patients in the NAP group were not seen by a rheumatologist.

One limitation of this study is the relatively low rate of response, especially in the NAP-group. Whereas more than two thirds of AP in our cohort completed the questionnaires, the NAP were provided a mail-back survey, and showed a response rate of only 44%. However, our results were comparable to findings in the literature: van Horn *et al*. report comparable results in a meta-analysis of survey response rates in published research over a 20-year span and describe a weighted average response rate of 49.6% (34). Another mail-back study with the goal to estimate the impact of non-response on evaluation of patient satisfaction with medical and nursing care showed very comparable responder rates to ours with 45% (35). The study demonstrated that non-response does not affect satisfaction measurement.

Comparison to literature was difficult, since most follow-up studies report drop-out rates taking only early rheumatoid arthritis into account, and not early arthritis of any origin. The VEAC was anticipated to include very early arthritis of any kind with symptom duration of no more than 12 weeks therefore including diagnoses of self-limiting character, resulting in higher "natural" drop-out rates. As reported before in a study in which the study population was derived from the same cohort (36), 60% of our patients are diagnosed with RA, and of these drop-out rates were 13% within the first year, 31% in the second year, therefore somewhat comparable to findings in other cohorts. (10, 23, 24) When considering the reasons for discontinuation we found in our study, it seems of utmost importance to question the administrative process in our clinics especially because our data suggest that patients are provided with better care when they remain in our clinics. University/hospital-based clinics have many advantages: studies show that patients are more satisfied with care in hospital-based clinics than with primary care (37), that application of research findings in clinical care is quicker (38), that patients have access to multifocal expertise and that the majority even welcomes the presence of students during their consultation (37). According to our findings, the disadvantage, from a patients' perspective, is mainly the lack of continuous care. Due to physicians' rotations between inpatient and outpatient care, laboratory/basic scientific work and teaching, the team in charge of outpatient clinics changes relatively frequently. Also, there is open access to clinics for patients with acute conditions or pain, at times leading to long waiting hours for those with long-ahead scheduled visits. Since these findings are unlikely to be a specific problem of local circumstances, but can be translated to many University/Hospital-based settings, it seems crucial to focus on improvement of the conditions criticised by the patients leading to discontinuation of attendance in clinics.

Taken together, our study demonstrates advantages in both disease activity measures and satisfaction with health care for patients receiving continuous care in the framework of a highly specialised rheumatology clinic.

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