

# Evaluation of collected outcome measures in axial spondyloarthritis in daily-care rheumatology settings: the experience of the RHEVER network

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## Abstract Objective

Nowadays, the recommended measures for optimal monitoring of axial Spondyloarthritis (ax-SpA) disease activity are either BASDAI and CRP, or ASDAS-CRP. However, there could be a gap between recommendations and daily practice. We aimed to determine the measures collected by rheumatologists in an ax-SpA follow-up visit, and to determine the impact of a meeting (where rheumatologists reached a consensus on the measures to be collected) on the collection of such measures.

## Methods

A consensual meeting of a local network of 32 rheumatologists proposed, four months later, to report at least the BASDAI score in the medical file of every ax-SpA patient at every follow-up visit. An independent investigator reviewed the medical files of 10 consecutive patients per rheumatologist, seen twice during the year (e.g. before and after the meeting). The most frequently collected measures were assessed, and then, the frequency of collection before and after the meeting was compared.

## Results

A total of 456 medical files from 228 patients were reviewed. Treatment (>60%), CRP (51.3%) and total BASDAI (28.5%) were the most reported measures in medical files. Before/After the meeting, the frequencies of collected measures in medical files were 28.5%/51.7%, 51.3%/52.2%, 16.7%/31.6% and 0.9%/6.1% for BASDAI, CRP, BASDAI + CRP and ASDAS, respectively reaching a statistically significance for BASDAI, ASDAS and BASDAI+CRP ( $p < 0.05$ ).

## Conclusion

This study revealed a low rate of systematic report of the recommended outcome measures in ax-SpA. However, it suggests that a consensual meeting involving practicing rheumatologists might be relevant to improve the implementation of such recommendations.

## Key words

axial spondyloarthritis, BASDAI, assessment, daily-practice

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## Introduction

Recommendations for disease assessment and follow-up in axial SpondyloArthritis (ax-SpA) are available for clinical trials, but also for daily practice follow-up (1–5).

The most recent 2014 recommendations for follow-up of ax-SpA established that disease activity should be measured on the basis of clinical signs and symptoms, and acute phase reactants: *e.g.* either by BASDAI and CRP or by the Ankylosing Spondylitis Disease Activity Score (ASDAS) that combines both aspects (symptoms and acute phase reactants) (4, 6).

However, it is well known that a gap frequently exists between recommendations and their implementation in real-life daily practice (7–9). One of the reasons that might explain this gap is the limited time that is often available in real-life visits, that does not allow to apply the “state of the art” of recommendations; another reason might be that the physicians/experts (*e.g.* more academic-oriented physicians) in charge of creating these recommendations are not the ones dealing with or applying these on a daily basis (*e.g.* more clinic-oriented physicians).

In this sense, several strategies have been suggested to increase the adherence from physicians to recommendations, one of these being that first-line physicians (*e.g.* general practitioners but also office-based specialists) should be more involved in the conception of such recommendations (*e.g.* as focus groups) to increase adherence (10–12). Only few studies have aimed to evaluate the measures collected by the rheumatologists in real-life clinical practice for the follow-up of ax-SpA, the real implementation of such recommendations in real-life, or the potential impact of involving the practitioners in the recommendations implementation, in order to increase adherence to these ends (12–14).

Thus, we decided to conduct a study aiming: a) to determine the most frequently collected measures by rheumatologists in the medical file of an ax-SpA follow-up visit in daily practice, and the predisposing factors of measures collection, and b) to determine the po-

tential impact of a consensual meeting during which rheumatologists achieved a consensus on how to implement such recommendations at the local level, and particularly on the measures to be collected for ax-SpA follow-up.

## Methods

### Study setting

RHEVER (*Réseau Hôpital Et Ville En Rhumatologie*) is the French acronym for hospital- and office-based rheumatologists network, and includes 32 rheumatologists in Paris. RHEVER meets three to four times a year to agree on standardised operational procedures for diagnosis/treatment and follow-up of patients suffering from rheumatic diseases (15–17). Indeed, the network aims at improving the standards of patient healthcare through educational programs and professional practice assessments (16).

During the June 2013 RHEVER meeting, both the results of a systematic literature review about recommendations on measures to be collected systematically during follow-up visit of ax-SpA patients and the results of a survey sent to the rheumatologist members of the RHEVER network, were presented. The debate following such presentation resulted in a consensus proposing the BASDAI score as the mandatory measure to be systematically collected during an ax-SpA follow-up.

Four months later, during the October 2013 RHEVER meeting, it was decided to conduct this study. It is worth highlighting that, in June 2013, no clinical study was planned. An independent investigator (H.C., not a RHEVER member) went to the offices (of office-based rheumatologists), reviewed the medical files of up to 10 consecutive unselected ax-SpA patients per member of the network seen during their routine-care visits (either office-based or hospital-based).

Patients (up to 10 per member) considered as suffering from an ax-SpA according to the opinion of the rheumatologist were enrolled. We asked the rheumatologists to provide medical files of patients with ax-SpA that could respond to ASAS (Assessment in SpondyloArthritis international Society) criteria according to them. During

Competing interests: none declared

the study, the independent investigator checked in the medical file of the enrolled patients, the information permitting to evaluate whether they were satisfying the ASAS criteria.

Only the files of patients seen twice in the year (*e.g.* during the 6 months preceding and the 6 months following the consensual meeting) were analysed. This meant that some files from patients seen after the October 2013 meeting (*e.g.* after the conduction of the study was decided) were also retained.

#### Data collection

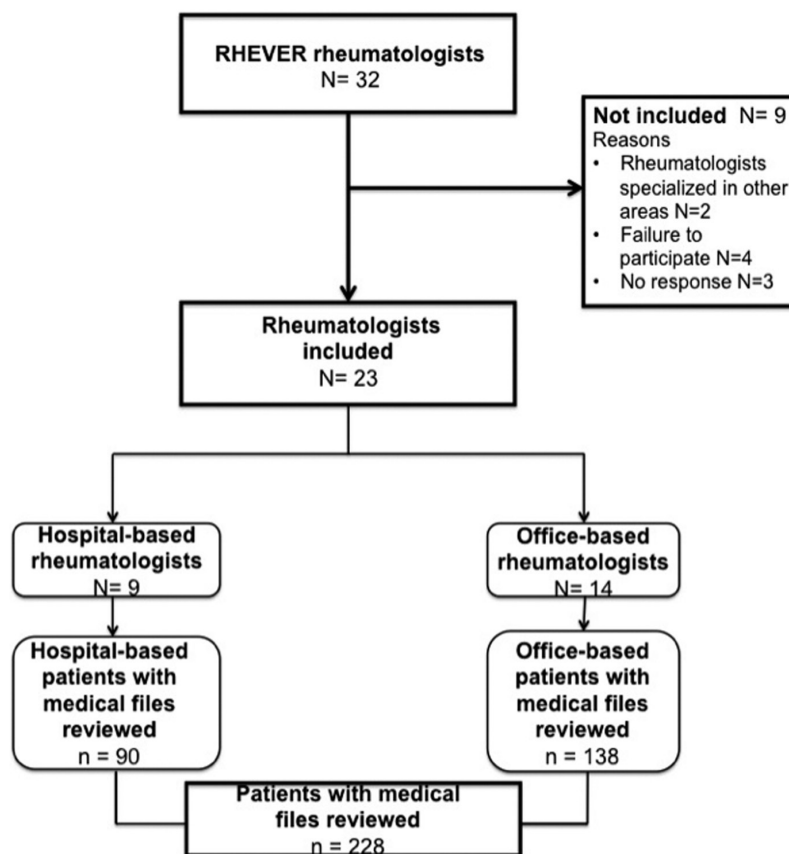
The characteristics of the rheumatologists participating to the study (age, gender, practice setting (office vs. hospital), years of practice, number of patient-visits/week and percentage of SpA patients among these) were collected. Then, for each medical file, patients' characteristics (age, gender, follow-up setting, date of diagnosis, date of symptoms onset and the ASAS criteria fulfilment) were collected. For the two visits (before and after the meeting), the availability in the medical file of measures recommended for optimal disease follow-up (1-3, 6) was checked: BASDAI total score but also each individual question, global pain, nocturnal awakening, ESR, CRP, ASDAS, tender and swollen joint counts, enthesitis examination, BASFI, BASMI and other metrology measures, hip range of mobility and informations on treatment (analgesics, non steroidal anti-inflammatory drugs (NSAIDs), corticosteroids, biologics and physiotherapy).

#### Statistical analysis

First, a descriptive analysis of the rheumatologists and of the ax-SpA patients was performed.

Afterwards, the frequency of collection for each measure before and after the meeting was compared by McNemar test for paired data. Statistical significance was established if  $p < 0.05$ .

Predictors of BASDAI score collection in the medical file (*e.g.* all characteristics of patients and of rheumatologists as detailed above), before the meeting, were explored by logistic regression, initially, univariate and, afterwards, multivariate, including in the model



**Fig. 1.** Flow chart of the rheumatologists and medical files included in the study  
N: number of rheumatologists; n: number of patients, ax-SpA: axial spondyloarthritis; Hospital-based files in a tertiary care/university hospital. Up to 10 patients with medical files reviewed per rheumatologist. One office-based rheumatologist provided 8 patients.

only the variables with  $p < 0.10$  in the univariate analysis.

The statistical analysis was performed using the free software R (v.3.0.2).

#### Results

Twenty-three RHEVER members accepted to participate: 9 (39%) were hospital-based and 14 (61%) office-based (Fig. 1), with a mean age of 51.6 ( $\pm 10.3$ ) years, predominantly males (57%), with 22.2 ( $\pm 10.3$ ) years of practice and visiting a mean of 61.9 ( $\pm 37.1$ ) patients per week; (17.4% ( $\pm 17.8\%$ ) of them suffering from ax-SpA).

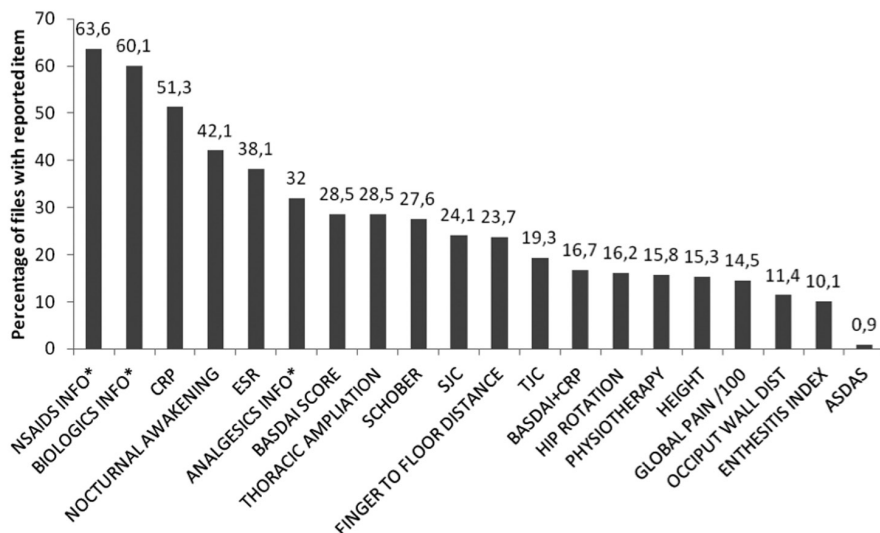
Four hundred and fifty-six medical files issued from 228 ax-SpA patients were reviewed. Characteristics of the ax-SpA population are resumed in Table I. There were 81 (35.5%) women, with a mean age of 44.4 ( $\pm 12.6$ ) years old and a mean duration disease of 11.7 ( $\pm 10.7$ ) years and 137 patients (60.1%) were treated with TNF-blockers. Among the 228 patients, 209 (91.7%) responded to

the ASAS criteria for ax-SpA (imaging or clinical), 2 (0.9%) patients did not respond to and for 17 (7.4%) patients the items permitting the classification were missing.

**Table I.** Characteristics of the ax-SpA population.

Characteristics	Ax-SpA patients n=228
Age, yrs N( $\pm$ SD)	44.4 (12.6)
Gender (% female)	81 (35.5%)
ASAS criteria	
-imaging ASAS (%)	175 (76.8%)
-clinical ASAS (%)	34 (14.9%)
Not responding to ASAS criteria	2 (0.9%)
Missing data	17 (7.4%)
Duration of disease, yrs	11.7 (10.7)
BASDAI (0-100) ( $\pm$ SD)	31.1 (22.5)
CRP (mg/L) ( $\pm$ SD)	10.9 (25.1)
TNF alpha blockers treatment (%)	137 (60.1%)

Ax-SpA: Axial spondyloarthritis; n: number of patients; yrs: years; SD: standard deviation; ASAS: Assessment in SpondyloArthritis Society; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; CRP: C-reactive protein.



**Fig. 2.** Most frequently reported measures in the medical file of ax-SpA patients. Only measures reported in at least 10% of files are included in this figure (except ASDAS).

NSAIDS: Non Steroidal Anti-Inflammatory Drugs; info\*: either the name of the drug or the intake was collected; CRP: C Reactive Protein; ESR: Erythrocyte Sedimentation Rate; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; SJC: Swollen Joint Count; TJC: Tender Joint Count; ASDAS: Ankylosing Spondylitis Disease Activity Score.

**Table II.** Predisposing factors for BASDAI collection before the consensual meeting in a multivariate analysis.

	Odds ratio	p-value
Rheumatologist's characteristics		
Years of practice	0.97 [0.93 – 1.01]	0.174
Percentage of SpA patients in practice population	1.01 [0.98 – 1.04]	0.569
Patient's characteristics		
Office-based follow-up	0.28 [0.11 – 0.69]	0.006

Only variables with  $p < 0.10$  in the univariate analysis were included for the multivariate analysis. SpA: spondyloArthritis; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index.

*Measures collected in a routine-care follow-up of ax-SpA patients.*

*1. Frequency of collection*

The frequency of collection of such measures before the consensual meeting is summarized in Figure 2.

Information about treatment, acute phase reactants and total BASDAI were the most reported measures. Indeed, information about NSAIDs and biologics intake was reported in more than 60% of medical files. CRP and ESR were found in 51.3% and 38.1% of medical files respectively. BASDAI score was then reported in 28.5%, BASDAI+CRP in 16.7%, while ASDAS-CRP was only collected in 0.9% of medical files.

*2. Predisposing factors for BASDAI collection before the consensual meeting*  
BASDAI collection before the meeting was significantly associated with the fol-

low-up setting (OR=0.18 [95%CI 0.10–0.33] for office-based rheumatologists) and the percentage of SpA patients in total practice population (OR=1.05 [95%CI 1.03–1.08]). This suggested that the BASDAI score was more frequently reported by hospital-based rheumatologists and by rheumatologists dealing more frequently with SpA patients. Moreover, BASDAI collection was also inversely significantly associated with the years of practice (OR= 0.94 [95%CI 0.91–0.97]) in the univariate analysis, suggesting that younger rheumatologists were more frequently reporting the BASDAI score.

However, the multivariate analysis only picked up the practice setting as a factor associated with BASDAI collection (OR=0.28 [95%CI 0.11 – 0.69] for office-based rheumatologists) (Table II).

*Impact of the meeting*

*1. on the BASDAI collection*

BASDAI collection was significantly increased after the meeting: BASDAI was collected in 65 (28.5%) medical files before the meeting, and its collection increased to 118 (51.7%) ( $p < 0.001$ ) after the consensual meeting (Fig. 3). For the individual questions of the BASDAI, questions 1, 3 and 5/6 were significantly more frequently collected after the meeting (Fig. 3).

Furthermore, we explored whether the fact that rheumatologists were aware of the conduct of the study (decision taken in October 2013) had an impact on the measures collection (55 patients (24.1%) were seen after the October RHEVER meeting): there was no difference in the increase of BASDAI collection in the medical files of patients seen between June 2013 and October 2013 (before the study was decided) and between October 2013 and January 2014 (after the study was decided), from 54 (31.2%) to 84 (48.5%) and from 11 (20.0%) to 34 (61.8%), respectively ( $p = 0.108$ ).

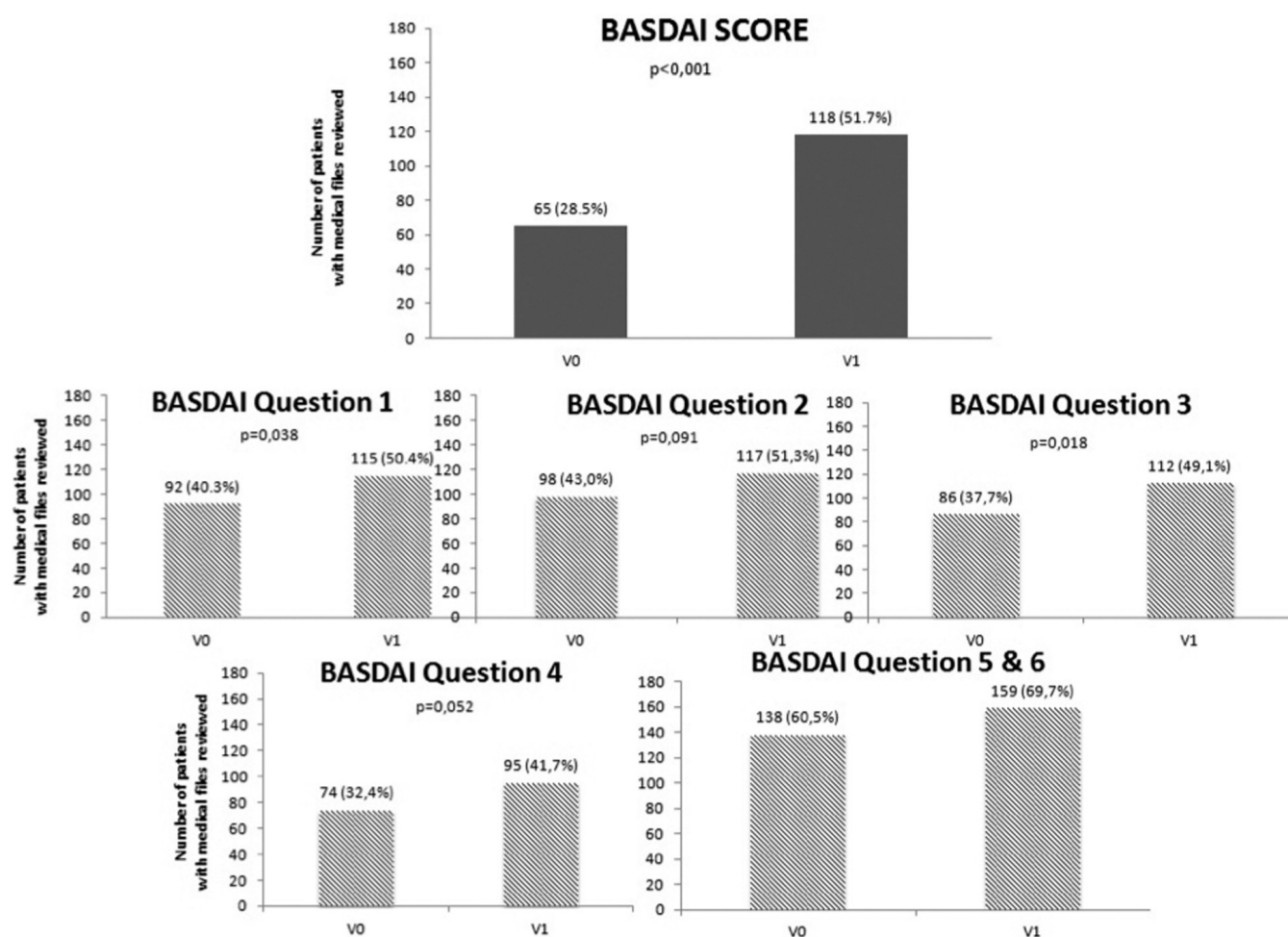
*2. on other measures collection*

A statistically significant increase in the frequency of ASDAS-CRP (from 0.9% to 6.1%,  $p = 0.0051$ ), of both BASDAI and CRP (from 16.7% to 31.6%,  $p = 0.0010$ ) and of Schöber's test (from 27.6% to 38.6%,  $p = 0.0169$ ) collection was observed (Table III). No statistical difference in the collection of other measures before and after the consensual meeting was detected.

**Discussion**

This study allowed us a) to identify the most frequently reported measures in a routine-care follow-up ax-SpA visit, and b) to confirm the interest of an agreement at the local level on how to implement the recommendations for the measures to be collected for ax-SpA follow-up in daily practice.

Our study found that the information related to the BASDAI score was only available in one third of the visits made by rheumatologists for ax-SpA patients. Such findings confirm that a gap exists between recommendations and their implementation in daily practice. How-



**Fig. 3.** Comparison of the number of medical files where BASDAI was reported before and after the consensual meeting.

\*: results are presented in N (%) number of medical files (%).  $p$  significant if  $< 0.05$ .

BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; V0: Visit before the consensual meeting of June 2013; V1: Visit after the consensual meeting of June 2013; N: number of patients.

ever, after the agreement at the local level during the meeting, total BASDAI collection dramatically increased (from 28.5% to 51.7%,  $p < 0.001$ ). It is worth noting that, in several cases, the calculated BASDAI score was not reported in the medical file but individual components were, so BASDAI total score could have been calculated. This was not taken into account into our analysis, but it means that potentially the number of visits with available information related to the BASDAI measures was greater.

Interestingly, the most frequently reported measures were treatment, CRP and BASDAI, but the frequency of collection of most measures (except BASDAI) remained stable after the meeting: only measures sparsely collected before the meeting, such as the ASDAS-CRP, the combination of BASDAI and CRP

and the Schöber test measure, were more frequently reported after the meeting.

Furthermore, office-based rheumatologists were less likely to collect BASDAI before the consensual meeting but the impact of this meeting on the reporting of BASDAI was greater in this group (data not shown).

Our study has some limitations but also some strengths.

Firstly, a bias on the recruitment of rheumatologists might exist, since all of them belonged to an organized local network and attended meetings regularly; however, a great proportion of these rheumatologists were office-based, and it is indeed in this setting where adherence to recommendations is usually lower, as reflected by the association between office-based rheumatologists and a lower collection of BASDAI, for the

potential following reasons: the lack of time, the organisation of the structure.

Secondly, we chose to retain only the files of patients that were seen twice within the 6 months before and after the meeting, and this may have led to a selection bias, as we might have retained only patients with more severe disease requiring a tighter control, as reflected by the 60% TNF-alpha blockers prescription of our study population, which is not the usual rate of TNF-alpha blockers intake among general ax-SpA population.

Also, the quite short follow-up period (6 months) did not allow us to confirm our observed results over an extended period of time.

Another potential limitation is that 55 (24.1%) of the files reviewed after the consensual meeting belonged to patients seen while rheumatologists were

**Table III.** Frequency of collection of other measures before and after the consensual meeting.

Follow-up measures	Before the consensual meeting	After the consensual meeting	p-value
Global Pain /100	33 (14.5%)	40 (17.5%)	0.4435
Nocturnal Back Pain /100	11 (4.8%)	13 (5.7%)	0.8339
Disease Activity /100	18 (7.9%)	29 (12.7%)	0.1235
Nocturnal Awakening	96 (42.1%)	105 (46.0%)	0.4505
Tender Joint Count	44 (19.3%)	52 (22.8%)	0.4214
Swollen Joint Count	55 (24.1%)	73 (32.0%)	0.0764
Enthesitis Index	23 (10.1%)	31 (13.6%)	0.3103
BASFI /100	13 (5.7%)	17 (7.4%)	0.5709
BASMI/100	0 (0.0%)	0 (0.0%)	-
Cervical Rotation	14 (6.1%)	15 (6.6%)	1.0000
Tragus Wall Distance	17 (7.4%)	24 (10.5%)	0.3260
Lateral Spinal Flexion	14 (6.1%)	13 (5.7%)	1.0000
Schöber	<b>63 (27.6%)</b>	<b>88 (38.6%)</b>	<b>0.0169</b>
Intermalleolar Distance	0 (0.0%)	0 (0.0%)	-
Thoracic Ampliation	65 (28.5%)	68 (29.8%)	0.8367
Occiput Wall Distance	26 (11.4%)	30 (13.1%)	0.6686
C7 Wall Distance	21 (9.2%)	25 (11.0%)	0.6409
Height	35 (15.3%)	43 (18.9%)	0.3840
Finger To Floor Distance	54 (23.7%)	76 (33.3%)	0.0694
L3 Wall Distance	9 (3.9%)	18 (7.9%)	0.1124
Hip Rotation	37 (16.2%)	37 (16.2%)	1.0000
PASS	0 (0.0%)	9 (3.9%)	1.0000
ASDAS-CRP	<b>2 (0.9%)</b>	<b>14 (6.1%)</b>	<b>0.0051</b>
BASDAI + CRP	<b>38 (16.7%)</b>	<b>72 (31.6%)</b>	<b>0.0010</b>
CRP	117 (51.3%)	119 (52.2%)	0.9253
ESR	87 (38.1%)	88 (38.6%)	1.0000
Analgesics Info*	73 (32.0%)	76 (33.3%)	0.8417
NSAID Info*	145 (63.6%)	152 (66.7%)	0.5555
Corticosteroids Info*	20 (8.9%)	19 (8.3%)	1.0000
Biologics Info*	137 (60.1%)	146 (64.0%)	0.4401
Physiotherapy	36 (15.8%)	36 (15.8%)	1.0000

BASFI: Bath Ankylosing Spondylitis Functional Index; BASMI: Bath Ankylosing Spondylitis Mobility Index; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; PASS: Patient acceptable symptom state; CRP: C-reactive protein; ESR: erythrocyte sedimentation rate; ASDAS: Ankylosing Spondylitis Disease Activity Score; NSAIDS: non-steroidal anti-inflammatory drugs; info\*: either the name of the drug or the intake was collected.

already aware that their files would be reviewed, and this could have lead to a difference in their daily practice. However, when comparing the frequency of BASDAI report in these files to the files belonging to patients seen when rheumatologists were not aware of the study, no differences were found. This suggests that this increase did only obey to a greater adherence to the local (and consensually-approved) implementation of recommendations. In this sense, a study published by Foy *et al.* (18) underlined the fact that a meeting consisting on formal program (reading and lectures) had little impact on the improvement of the adherence of physicians, whereas interactive programs allowing physicians to participate actively increased such adherence. Interestingly, collection of outcome measures are important in daily prac-

tice since they are relevant to evaluate effectiveness of different treatments and also drug maintenance (19).

**Conclusion**

Our study suggests that:

- a) the most frequently collected measures in ax-SpA follow-up files concerned treatment, CRP and BASDAI.
- b) a gap between recommendations for such follow-up and its implementation in daily practice exists, but that a meeting in which a network of rheumatologists agreed on how to implement these recommendations lead to a 2-fold increase in the BASDAI collection. Further studies are required in order, firstly, to confirm or not these results in different settings/countries, then to evaluate other tools permitting to facilitate the implementation of such recommendations and finally to evalu-

ate the sustainability of the effect of the meeting we have organised on the collection of recommended outcome measures.

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