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# ASAS/EULAR recommendations for the management of ankylosing spondylitis: the patient version

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## ABSTRACT

**Background:** The ASAS/EULAR (Assessment of SpondyloArthritis International Society/European League Against Rheumatism) recommendations for the management of ankylosing spondylitis (AS) have been developed by rheumatologists for a target population of health professionals.

**Objective:** To extend the cooperation between ASAS and EULAR by translating the recommendations into a language that can be easily understood by patients in order to further disseminate and evaluate the recommendations.

**Methods:** In cooperation with patient organisations 18 patients with AS (17 European, one Canadian) were invited to attend a meeting in February 2008. As a starting point the original publication and a version created by Canadian patients with AS were used. To improve the understanding of potential problems, data on the evaluation of a recent German translation were presented. After intensive discussions the wording was adjusted and a vote was held on the new wording of the recommendations aiming for >80% agreement on each sentence. Finally, patients were asked to indicate their level of agreement with the content of the recommendations.

**Results:** Ten recommendations were successfully translated into a patient-understandable version. The original text was changed in most cases. In all but one case (recommendation No 4) there was broad agreement with the proposed translation. The overall agreement with the content of the recommendations was high: 8.7 (0.6).

**Conclusion:** For the first time, EULAR recommendations were successfully converted into a patient-understandable language version by a large international group of patients in collaboration with rheumatologists. The evaluation showed broad agreement. Translations into different languages and further dissemination in individual countries will be performed.

Ankylosing spondylitis (AS), the main entity of the spondyloarthritides, is a chronic inflammatory disease characterised by specific musculoskeletal features: inflammation and ankylosis of the axial skeleton, peripheral arthritis, enthesitis and involvement of other organs such as the eye.<sup>1</sup> Major advances in the management of AS have recently been made by introduction of magnetic resonance imaging (MRI) and the tumour necrosis factor (TNF) $\alpha$  inhibitors.<sup>2-3</sup> To assist all health professionals involved in the care of patients with AS, evidence-based recommendations for the management of this disease were developed.<sup>4</sup>

The Assessment of SpondyloArthritis International Society (ASAS) has published recommendations for

the use of anti-TNF therapy in AS,<sup>5</sup> and together with the European League Against Rheumatism (EULAR) recommendations for the management of AS in 2006 (supplementary data 1 and 2, available online) based on a systematic literature search.<sup>6,7</sup> These were drafted by a combination of evidence and expert consensus. Treatment recommendations for AS have also been released by the Canadian Rheumatology Association/Spondyloarthritis Research Consortium of Canada working group.<sup>8,9</sup>

The ASAS/EULAR recommendations were an important step forward in generating an international consensus on the appropriate management of AS. However, they have been developed by rheumatologists and orthopaedic surgeons for a target population of mainly health professionals and payers, and the language of the publication is largely medical. In a chronic disease, sustainable patient knowledge is beneficial and patient input into the decision-making process of recommendations is a requirement by various institutions. The importance of patients' views and preferences is also included in the Appraisal of Guidelines for Research and Evaluation (AGREE) instrument for evaluation of guidelines.<sup>10</sup> However, the mechanism by which this is best accomplished has not been well defined.

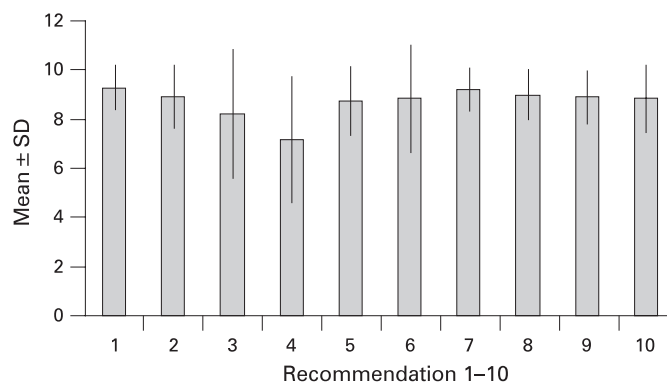
ASAS and EULAR have agreed to extend their cooperation by translating recommendations into a language that can be easily understood by patients. At a consensus meeting of rheumatologists and deputies of national patient organisations, the ASAS/EULAR recommendations for the management of AS were translated into a language that can be understood by patients with AS in order to further disseminate and evaluate the recommendations among patients.

## METHODS

### Participants

In cooperation with EULAR (PARE, People with Arthritis/Rheumatism in Europe), the Ankylosing Spondylitis International Federation (ASIF), the Deutsche Vereinigung Morbus Bechterew (DVMB), the National Ankylosing Spondylitis Society (NASS) and other national patient organisations, 18 patients with AS (including one rheumatologist) of 10 different countries (Belgium, Canada, Germany, Ireland, the Netherlands, Portugal, Romania, Switzerland, Turkey, United Kingdom) were invited to attend a consensus meeting at the EULAR house near Zurich in February 2008. A planning committee was formed from within ASAS (J Braun as convener, D van der Heijde as clinical epidemiologist, H Mielants as an experienced clinician and

## Recommendation



**Figure 1** Strength of recommendations 1–10.

ASAS member), EULAR (M de Wit) and ASIF (E Feldtkeller). Demographic characteristics, partial history and current health status of the participants were collected. This included questions to be answered by a visual analogue scale, the Bath AS Disease Activity Index (BASDAI) and the Bath AS Functional Index (BASFI).

### Working document

As a starting point, the original publication and a version created by Canadian patients with AS were used. K Mulholland, a patient with AS who was strongly involved in the Canadian

project, attended the meeting to explain the development of this patient-based version.<sup>9</sup> To improve the understanding of potential problems, data on the evaluation of a recent German translation of the experts version evaluated by patients were presented during the meeting.<sup>11</sup>

### Translation process

Each participant of the consensus meeting was asked to contribute independently proposals relevant to translation of the patient version of the ASAS/EULAR recommendations for the management of AS. The aim was to create a new manuscript that was produced and understood by patients. To achieve this, the main task was to translate the original text by simplifying the wording and to explain the original text by adding comments to a patient-friendly version. However, it was stated at the beginning of the meeting that modification of the meaning of the original recommendations was not allowed. After the participants had generated 10 patient-adapted recommendations, comments explaining difficult terms were discussed and a wish list was developed for possible consideration in the next update of the ASAS/EULAR recommendations for the management of AS.

### Evaluation

After intensive discussions a vote was held on the new translation of the recommendations aiming for >80% agreement on the translation. The participants had the option to

**Table 1** Characteristics of the participants (17/18 with available data)

Category	Specific characteristics	Comment	Value
General data	Men, No (%)		14 (82)
	Age (years), mean (SD)		51.5 (15.5)
Diagnosis	Disease, No (%)		Axial AS: 10 (59%) AS with peripheral arthritis: 6 (35%) AS and ulcerative colitis: 1 (6%)
	Time since diagnosis (years), mean (SD)		24.5 (12.6)
	Disease duration since symptom onset (years), mean (SD)		28.6 (14.6)
Disease activity	BASDAI, mean (SD)		3.3 (2.1)
	BASFI, mean (SD)		3.5 (2.0)
	VAS pain, mean (SD)		3.3 (2.6)
Pain medication	Overall, No (%)	At least one	15 (88)
	NSAIDs, No (%)	Regular	7 (41)
		On demand	6 (35)
		On demand	3 (18)
	Opioids, No (%)	Regular	2 (12)
Corticosteroids	Oral, No (%)	Regular	1 (6)
		On demand	2 (12)
DMARDs	Overall, No (%)		7 (41)
	Sulfasalazine, No (%)		2 (12)
	Methotrexate, No (%)		1 (6)
	Anti-TNF therapy		4 (24)
Surgery	Total hip replacement		1 (6)
	Corrective osteotomy		1 (6)

AS, ankylosing spondylitis; BASDAI, Bath AS Disease Activity Index; BASFI, Bath AS Functional Index; DMARDs, disease-modifying antirheumatic drugs; NSAIDs, non-steroidal anti-inflammatory drugs; TNF, tumour necrosis factor; VAS, visual analogue scale.

**Box 1 Recommendations for the management of ankylosing spondylitis (AS) in lay language****Recommendation 1: General principles for management**

The treatment of AS should be specifically adapted for individual patients according to:

- ▶ How the disease currently affects the patient (spine, joints, attachments of ligaments and tendons\*, other locations\*)
- ▶ The level of current symptoms, findings on examination and features that predict how the disease may progress, as indicated by:
  - disease activity\*/inflammation
  - pain
  - function and disability
  - damage to the spine and hip\*†
- ▶ The general medical condition (age, sex, other diseases, medication)
- ▶ The patient's wishes and expectations

**Recommendation 2: Disease monitoring**

- ▶ Disease monitoring\* should relate to the patient's current health. It includes patient history (eg, questionnaires), physical examination, laboratory tests and imaging\* (eg, x-rays), based on the core set\* of measurements recommended by ASAS\*
- ▶ The frequency of monitoring should be decided for each individual patient based on current symptoms, severity and medication

**Recommendation 3: Management strategy**

Optimal management\* of AS requires the use of both drug and non-drug treatments

**Recommendation 4: Non-drug treatment**

Non-drug treatment of AS should include patient education† and regular exercise. Individual and group physiotherapy† under the supervision of a qualified therapist should be considered. Patient associations and self-help groups† may be useful

**Recommendation 5: Drug treatment: anti-inflammatory drugs**

- ▶ Anti-inflammatory drugs\* (not including steroids) are recommended as first choice for patients with AS suffering from pain and stiffness
- ▶ For patients with an increased risk of side effects in the stomach there are two options:
  - an additional drug that protects the stomach, or
  - an anti-inflammatory drug with a reduced risk for side effects in the stomach (selective COX-2 inhibitor\*)

**Recommendation 6: Drug treatment: pain killers**

Pain killers such as paracetamol and opioids\* might be considered for pain control when anti-inflammatory drugs:

- ▶ Have not provided sufficient relief
- ▶ Have caused unacceptable side effects
- ▶ Cannot be used because of other medical reasons

**Recommendation 7: Drug treatment: steroids**

- ▶ Local injections of steroids\* at the site of inflammation\* may be considered
- ▶ The benefit of steroids given in other ways is not proven when the disease is only present in the spine

**Recommendation 8: Drug treatment: DMARDs**

- ▶ It is not proven that so-called disease-modifying antirheumatic drugs (DMARDs\*), such as sulfasalazine† and methotrexate, are effective for the treatment of AS in the spine

- ▶ Sulfasalazine may be effective in those patients who have inflammation in joints outside the spine

**Recommendation 9: Drug treatment: anti-tumour necrosis factor (anti-TNF)**

- ▶ If the treatments outlined above do not control disease activity sufficiently, anti-TNF\* drugs should be given in line with the ASAS recommendations\*
- ▶ It is not necessary to use DMARDs before or together with anti-TNF treatment in those patients who only have disease in the spine

**Recommendation 10: Surgery**

- ▶ Total hip replacement\* should be considered, regardless of age, in patients with pain or disability not responding to treatment and where there is x-ray evidence of joint damage
- ▶ Spinal surgery may be of value to correct severe deformity\* or stabilise\* the spine

\*See comments 1–10 (table 2); †see wish-list (table 4).

agree (positive vote), to disagree (negative vote) or to be neutral (no vote) on the translation of the patient version. When a vote was negative the participants were asked to state the reason for their disagreement. Finally, based on the content of the recommendation, patients were asked to rate the strength of recommendation on a numerical rating scale for each recommendation (0 = do not agree at all, 10 = fully agree).

Figure 1 gives the strength of each recommendation as assigned by the participants.

**RESULTS****Characteristics of the participants**

The baseline characteristics of the participants are given in table 1.

**Translation and evaluation of the patient version**

Ten recommendations were successfully translated into a patient-adapted version. The first three recommendations deal with general concepts in the management of AS, the remaining seven describe specific treatments in use for AS. The original text was changed in most cases.

Box 1 shows the full recommendations of the patient version; comments on each recommendation are presented in table 2, while the evaluation of the recommendations (translation and agreement) is shown in table 3.

Table 4 contains the wish list.

**Translation**

In general, common speech was preferred as a translation of Latin terms in the expert's version (eg, comorbidity → other diseases, concomitant drugs → medication (recommendation 1)). But not all medical language can be rendered in lay terms (eg, COX-2 inhibitor). In such cases, the term is commented on in table 2. We deleted words in some instances (like "structural" (recommendations 1 and 10) or "persistently" (recommendation 9) where the use or translation of these words did not contribute to a better understanding of the patient-adapted version.

To emphasise the heterogeneity of the clinical picture of AS, the term "current manifestation" in recommendation 1 was changed to "other locations" as explained in the "comments" section. The participants needed an explanation for the understanding of the

## Recommendation

**Table 2** Comments on recommendations 1–10

No	Text	Comment
1	Ligaments/tendons Other locations Disease activity Damage	Attachment of muscle to bone can become inflamed (enthesitis) Other areas, such as eyes, lungs, bowel, skin and heart can also become inflamed Measurement of how affected the patient is. Inflammation is an important part of disease activity In ankylosing spondylitis (AS) inflammation, bone destruction and aberrant bone repair coexist with extra bone formation. This causes a condition in the spine by which some or all vertebrae fuse together (ankylosis). Hip joint destruction is primarily characterised by inflammation followed by cartilage loss (coxitis)
2	Monitoring Imaging Core set ASAS	Monitoring is continuous observation and measurement of the patient to check AS continuously. It is more than merely patient follow-up Visualisation of body organs using specialised techniques like radiography, ultrasonography or magnetic resonance imaging Group of assessments used to quantify the symptoms of patients with AS Assessment of SpondyloArthritis International Society (ASAS) is an international society of experts in the field of spondyloarthritis
3	Management	Guidance of the patient including specific treatment options
5	Anti-inflammatory drugs COX-2 inhibitor	Non-steroidal anti-inflammatory drugs (NSAIDs) may have a pain-killing and anti-inflammatory effect. Long-term continuous treatment with NSAIDs may be beneficial in reducing radiographic progression in AS Selective cyclo-oxygenase-2 inhibitors are special types of NSAIDs that block the production of prostaglandins. They differ from NSAIDs by targeting only the pain-signalling prostaglandins. COX-2 inhibitors may act without causing stomach problems (eg, ulcers) often associated with other NSAIDs
6	Opioids	Opioids (eg, codeine) are powerful pain-killing drugs and these morphine-like drugs may be used to treat chronic pain. Opioid drugs do not cause addiction when used correctly for severe pain under close medical supervision
7	Steroids Site of inflammation	Corticosteroids are a group of anti-inflammatory drugs similar to the hormone cortisol produced in the body. Steroids work by blocking the production of substances in the immune system that trigger inflammatory reactions Local inflammation can occur in AS at many different musculoskeletal sites, including spine, joints outside the spine and enthesitis (see comment 1)
8	DMARDs	The term disease-modifying antirheumatic drugs (DMARDs) subsumes drugs which suppress the overacting immune system, but the exact mechanism of action is unclear. DMARDs work long term and can take several months to produce results
9	Anti-TNF ASAS Recommendation for anti-TNF treatment	Tumour necrosis factor (TNF) levels are elevated in patients with active AS. Anti-TNF drugs block this molecule and may help reduce inflammation ASAS recommendations for the use of anti-TNF drugs in patients with AS are developed for guidance in clinical decision making (see supplementary online data 2)
10	Total hip replacement Severe deformity Stabilisation	AS may lead to persistent hip damage requiring replacement with an artificial joint (prosthesis) In connection with the vertebral fusion of the spine (ankylosis) (see comment 1) the convexity of the thoracic spine can be abnormally increased (kyphosis). This may cause loss of horizontal vision without compensation. In rare cases surgery is used to restore a straighter posture of the spine Owing to the extra bone formation in the spine (see comment 1) and possible osteoporosis, the risk of instability and fracture is increased in the spine. In rare cases surgery is used to correct the instability

**Table 3** Evaluation of the recommendation

Recommendation		Translation			Evaluation	
No	Description	Agree, n (%)	Disagree	Neutral	SOR	Range
1	General principles for management	21 (100)	0	0	9.3 (0.9)	7–10
2	Disease monitoring	20 (95)	0	1	8.9 (1.3)	6–10
3	Management strategy	20 (95)	1*	0	8.2 (2.6)	0–10
4	Non-drug treatment	16 (76)	4†	1	7.2 (2.6)	1–10
5	Drug treatment: anti-inflammatory	20 (95)	0	1	8.3 (1.4)	5–10
6	Drug treatment: pain killers	20 (95)	0	1	8.8 (2.2)	1–10
7	Drug treatment: steroids	21 (100)	0	0	9.2 (0.9)	7–10
8	Drug treatment: DMARDs	21 (100)	0	0	9.0 (1.0)	7–10
9	Drug treatment: anti-TNF	21 (100)	0	0	8.9 (1.1)	7–10
10	Surgery	20 (95)	1‡	0	8.8 (1.4)	6–10
1–10	Overall agreement	21 (100)	0	0	8.7 (0.6)	N/A

See box 1 for the text of the recommendations.

\*Participant thinks that ankylosing spondylitis can be treated without medication in some cases; †participants think that the paragraph should be more positive, especially for physiotherapy and self-help groups; ‡participant thinks that a total hip replacement should not always be performed.

DMARDs, disease-modifying antirheumatic drugs; N/A, not applicable; SOR, strength of recommendation; TNF, tumour necrosis factor.

**Table 4** Wish list of the patients for possible consideration in the generation of the next update of the ASAS/EULAR recommendations for the management of ankylosing spondylitis (AS)

No	Text	Wish list	Main barrier
1	Damage of joints	One should mention not only the hip but also other joints.	Peripheral arthritis is usually oligoarticular and affects mainly the lower limbs. Hip involvement is reported as a bad prognostic sign
4	Education	<ul style="list-style-type: none"> <li>▶ Evaluation of non-pharmacological treatment should be given more importance</li> <li>▶ Non-pharmacological treatment needs further explanation of quality and quantity</li> <li>▶ Patient education should be improved</li> <li>▶ Communication between family doctor and specialist should be enhanced</li> </ul>	Insufficient data of non-pharmacological treatment, only 15% of studies reported effects of non-pharmacological treatment in AS Effect of isolated education for AS is not yet clear
	Physiotherapy	Appropriate exercise is crucial to managing AS. Regular home exercise is the basis of non-pharmacological treatment. Physiotherapy may be completed with other procedures (balneotherapy or electrotherapy)	Specific physical modalities have not been studied
	Self-help groups	Patients who take an active interest in their condition can positively influence the outcome of AS. Using practical advice of self-help groups to manage the condition is strongly recommended by stakeholders	Self-help groups have not been studied for their effect on pain or functional outcomes
8	Sulfasalazine	Comment on the role of sulfasalazine for the treatment of uveitis, inflammatory bowel disease, psoriasis	Additional to the role of sulfasalazine in peripheral arthritis associated with spondyloarthritis, sulfasalazine may play a role in the treatment of uveitis, inflammatory bowel disease, psoriasis, but there are insufficient data on these options

term “clinical” in recommendations 1 and 2. We consequently decided to change it to “findings on examination” or “medical condition”.

The term “function, disability, handicap” in recommendation 1 refers to the model of functioning developed by the World Health Organization (WHO). Most patients accepted dropping “handicap” in the patient-adapted version, deciding that handicap is included in the word “disability”.

For the division into non-pharmacological and pharmacological treatment options (recommendation 3) it was decided to generally change the word “pharmacological” to “drug” for better understanding. As the majority of the recommendations deal with pharmacological treatment, there was an intense discussion about several problems with understanding of, and agreement with, recommendations 5–9. Because participants expected that many non-health professionals would have difficulty understanding pharmacological terminology, we used the common term “anti-inflammatory” instead of non-steroidal anti-inflammatory drugs (NSAIDs), emphasising explicitly that this does not include corticosteroids. The experts and participants discussed the translation of “gastrointestinal” intensively. In the patient version the term “stomach” is used ignoring the potential intestinal side effects of NSAIDs. The terms “gut” and “bowel” were also discussed but the majority of the participants found the term “stomach” easier to understand. The structure of recommendation 5 and 6 was changed extensively for improved understanding.

### Evaluation

Agreement with translation of the recommendation was evaluated separately for each recommendation. In all but one case there was broad agreement with the proposed translation. Full agreement of all participants with the translation was achieved in recommendations 1, 7, 8 and 9. Not more than one disagreement was achieved in recommendations 2, 3, 5, 6 and 10. For recommendation No 4 disagreement was expressed by 4/18 participants (22%). However, this largely related to the content of the recommendation and not to the actual translation.

The overall agreement with the content of the recommendations was high (mean (SD) agreement: 8.7 (0.6)). Agreement was highest for recommendation 1 (general principles for management) and for recommendation 7 (drug treatment: steroids) (mean (SD) 9.3 (0.9) and 9.2 (0.9), respectively). Agreement was lowest for recommendation 4 (non-drug treatment) with a mean (SD) value of 7.2 (2.6).

### DISCUSSION

This is the first translation/transformation of EULAR recommendations into a patient-adapted version. This effort is a major step forward in the process of evaluation and dissemination to health professionals as well as to non-health professionals as required in the EULAR standardised operating procedures.<sup>12</sup> The original ASAS/EULAR recommendations for the management of AS published more than 2 years ago have already been evaluated in different countries.<sup>4 13–15</sup> In Canada, a first effort was undertaken to try this also at the patient level.<sup>9</sup> Support of patient knowledge and participation in the management of chronic diseases is likely to be beneficial since it is well established that one powerful strategy to change behaviour of patients is to involve them directly in the development of guidelines or recommendations.<sup>16</sup>

This is the first time that patient-adapted recommendations for the management of AS have been developed with direct participation of patients in a consensus meeting. In this way the 10 key recommendations of the expert’s version (online supplementary data 1) were successfully translated into a patient-understandable language (box 1). Indeed, the notable and most important experience in this meeting was that it was not a great problem to agree on this patient-adapted version of the recommendations for the management of AS among a rather mixed group of patients with AS from 10 different European countries. The involvement of patients with many different native tongues enhances the likelihood that the present language version can be easily understood by many patients and also easily translated into various languages as specific English wording is avoided. Although there was a lot of discussion, it was eventually possible to agree on the basis of a majority vote, with >80%

## Recommendation

agreement in almost all cases. Participants accepted that the basic content of the original recommendations could not be changed during this translation process. Considerable time was spent on discussions relating to the content of the recommendations (importance of non-pharmacological treatment options, use of opioids and corticosteroids, etc). The patients prepared a wish-list for further consideration in the next update of the recommendations, in which most of the discussion regarding the content is summarised (table 4). Although patients were aware that the content of the recommendation could not be changed, it is quite obvious that in some cases (eg, recommendation No 4) the patients vote on the translation was influenced by disagreement about the content of the recommendation. This difficulty can be reduced if the patients with AS are allowed to participate in the development of recommendations at an earlier stage.

This patient version of the ASAS/EULAR recommendation for the management of AS should serve as a preliminary step for the development of the ASAS/EULAR management recommendation update and also for further evaluation and dissemination in individual countries where a broader array of patients should be included. Thus, the patient version will be forwarded to ASAS members in all EULAR countries with the request that they perform a translation in cooperation with their national patient organisation. For this national translation process, the disease status and educational level of the group of participants should be heterogeneous. This was not the case in our group of patients with AS because the success of creating an international patient version depends on excellent knowledge of the English language of all participants. The dissemination and evaluation of the national patient versions will be checked after 1 year.

The participants stated during the discussion that factors other than body functions and structures have to be discussed as an important aspect of disease progress (recommendation No 1). According to the composition of the International Classification of Functioning, Disability and Health developed by the WHO for describing functioning of people with ill health, aspects of activity and participation of the patients have also to be considered.<sup>17</sup> In this framework, function is not narrowed to a biomedical function but environmental and personal factors are also taken into account. Recently, this was applied to patients with AS.<sup>18</sup>

The study on dissemination and evaluation of the health professionals' publication of the ASAS/EULAR recommendations for the management of AS among European rheumatologists has already shown that conceptual agreement with the recommendations was very high, as was self-declared application by rheumatologists (8.9 (0.9) and 8.2 (1.0), respectively).<sup>15</sup> Potential barriers to the application of the ASAS recommendations include primarily insufficient funding and administrative burden for anti-TNF therapy and patient concern about the safety of pharmacological therapy. Barriers to the use of the non-pharmacological treatment are lack of consultation time, insufficient number of qualified physiotherapists, lack of facilities for education and lack of patient compliance with recommendations. Similar to the European evaluation, a broad agreement with the recommendations was achieved by an evaluation in the German language area and in Mexico.<sup>14 15</sup>

For the first time, EULAR recommendations were successfully converted into lay terms by a large international task force of patients in collaboration with rheumatologists. This can be seen as a starting point for the dissemination and implementation of the patient version to provide guidance for monitoring and treatment of patients with AS. Further translations into different languages and appropriate evaluations in larger patient groups will be performed.

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## APPENDIX 1: LIST OF PARTICIPANTS

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