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Standardized reporting for systematic global evaluation of axial spondyloarthritis: An evidence-based and consensus-driven initiative

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1 **Standardized Reporting for Systematic Global Evaluation of Axial**
2 **Spondyloarthritis: An Evidence-Based and Consensus-Driven Initiative**

3

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54

55 **Highlights:**

- 56 • An annual review of patients with axial spondyloarthritis encompassing disease
57 activity, severity, comorbidities, employment, psychological factors, and lifestyle is
58 recommended.
- 59 • The specific content of this annual review has never been proposed.
- 60 • This initiative provided a reporting framework including all components needing to
61 be assessed during this review.
- 62 • This document was obtained after a literature search and an expert consensus-driven
63 approach.

64 **Abstract**

65 **Background:** National and international scientific societies advocate for a regular,
66 systematic, and standardized global evaluation of axial spondyloarthritis (axSpA) patients.
67 However, there are no recommendations specifying the content of this global evaluation.
68 This initiative aimed to propose a standardized reporting framework, using evidence-based
69 and consensus approaches, to collect data on all domains of axSpA.

70 **Methods:** A literature review and consensus process involved a steering committee and an
71 expert panel of 37 rheumatologists and health professionals. The first steering committee
72 took place in March 2022 and identified the main domains for inclusion in the standardized
73 report. A hierarchical literature review was conducted to identify items within these
74 domains and tools for assessment. The items and tools for assessment were discussed and
75 consensus was reached through a vote session during an expert meeting that took place in
76 March 2023.

77 **Results:** The steering committee identified four main domains to include in the standardized
78 reporting framework: disease assessment, comorbidities, lifestyle, and quality of life. Items
79 and tools for assessment were adopted after the expert meeting. Additionally,
80 recommendations regarding digital tools (websites, apps, social media) were provided.

81 **Conclusion:** This initiative led to a consensus, based on evidence and expertise, on a
82 reporting framework for use during periodic systematic global evaluations of axSpa in daily
83 practice.

84

85 **Keywords:** Spondyloarthritis; disease assessment; comorbidities; quality of life; e-health

86

87

88

89 **Introduction**

90 Axial spondyloarthritis (axSpA) is among the most prevalent chronic inflammatory
91 rheumatic diseases, primarily affecting young adults [1]. Poorly controlled disease
92 significantly impacts patients' quality of life, professional capacities, and healthcare costs [1,
93 2]. Extra-musculoskeletal features, such as psoriasis, uveitis, and inflammatory bowel
94 diseases, frequently co-occur and further affect the quality of life [1]. Additionally, patients
95 often experience comorbidities like atherosclerosis-related cardiovascular diseases,
96 infections, osteoporosis, or gastrointestinal manifestations [3, 4]. Advances in biological and
97 synthetic disease-modifying drugs have improved prognosis, but potential side effects
98 necessitate early detection and prevention [5].

99 Optimal patient management involves collaboration among various health professionals,
100 including rheumatologists, nurses, and physiotherapists, adopting a "global approach" [6].
101 Quality standards developed by the Assessment of SpondyloArthritis International Society
102 (ASAS) [7], recommend an annual comprehensive review for axSpA patients, encompassing
103 disease activity, severity, comorbidities, employment, psychological factors, and lifestyle.
104 However, specific assessment methods for these components are not detailed in the
105 recommendations. Moreover, ASAS recommended periodical systematic global review is far
106 from being implemented. It can be hypothesized that this lack of implementation might be
107 partly due to the non-availability of a tool (reporting framework) facilitating the task of the
108 rheumatology team. Another aspect of the management has also been emphasized: the
109 necessity for the rheumatology team to recommend (or not recommend) digital tools such
110 as websites, apps and social medias..., hoping to avoid wrong messages. However, the

111 systematic review and quality assessment of such digital tools in the axSpA field have never
112 been reported.

113 Previous task force [8, 9] attempted to define variables for systematic collection in ax-SpA
114 patients, but no consensus exists for a comprehensive review.

115 Addressing this gap, our initiative aimed to implement the ASAS quality of care standard,
116 focusing on a comprehensive annual review in a national context (France). We sought to
117 develop a pragmatic document (reporting framework) for use in clinical practice,
118 encompassing the collection and management of disease symptoms, comorbidities, lifestyle,
119 and quality of life.

120

121

122

123 **Methods**

124 This process included literature reviews and a consensus process following previous
125 initiatives (Rencontres d'Experts en Rhumatologie (RER) and 3E (evidence, expertise,
126 exchange)) [8-10]. The initiative was supported by an unrestricted grant from AbbVie France.

127

128 **Decisions on the domains and contents of the holistic evaluation that had to be discussed**

129 The process began with a face-to-face meeting on March 30th, 2022. The steering committee
130 included a convenor (MD), one scientific coordinator (ARW), one fellow for the literature
131 review (DCP), 14 rheumatologists, one pharmacist, one physiotherapist and one
132 rheumatology nurse. The committee identified four main evaluation domains: disease
133 assessment, comorbidities, lifestyle, and quality of life.

134

135 **Hierarchical systematic literature review**

136 A hierarchical systematic literature review was conducted from April to December 2022 to
137 identify relevant items for systematic collection during holistic evaluations. The review
138 prioritized data from international (European League Against Rheumatism (EULAR)/ ASAS
139 [11]) or national (French Society of Rheumatology (SFR)) scientific societies [6] and previous
140 RER initiatives [8, 9]. If none were available, the second step retrieved data in
141 recommendations from other medical specialities, systematic literature reviews or meta-
142 analysis. The third step focused on clinical trials and ax-SpA cohorts. As the search was
143 hierarchical, when relevant information was found at a specific step, the next steps were not
144 carried out.

145 A second face-to-face steering committee meeting on December 2nd, 2022 reviewed the
146 outcomes and decided to systematically include variables already selected in previous
147 recommendations. The other variables (for example, the way of collecting physical activity,
148 the way of collecting alcohol consumption, ...) were selected by the steering committee and
149 presented in a condensed form for discussion during the consensus process.

150

151 **Systematic review of digital tools for information of the patients**

152 A systematic evaluation of the digital tools available in French was also conducted by
153 another fellow (AN) permitting them to provide some advices to the patients (for example
154 which recommended webs sites). Quality criteria, based on EULAR recommendations [12]
155 and other groups [13-16], were used to assess websites, apps, videos, and connected
156 devices, with a focus on scientific validity, patient data confidentiality, and accessibility.

157

158 **Consensus process**

159 The consensus process, conducted in March 2023, involved 37 rheumatologists and health
160 professionals. Three parallel workshops, repeated twice, allowed experts to decide on
161 outcomes to include in the standardized report. Consensus was reached through workshops
162 and, if necessary, a plenary session vote.

163

164 **Finalization of the report frame and assessment of feasibility**

165 The finalized report frame was reviewed for feasibility by the steering committee. Each
166 member assessed the practicality of conducting a global evaluation and collecting required
167 variables for ax-SpA patients during outpatient visits or hospitalizations.

168

169 **Results**

170 **Hierarchical systematic literature analysis**

171 A total of 12 recommendations and 934 abstracts were retrieved by the searches, of which
172 38 were included in the final qualitative synthesis (see supplementary material) presented
173 during the final meeting.

174

175 **Disease evaluation (Table 1)**

176 It has been proposed to divide the optimal evaluation of the disease into four sections. The
177 contents of the reporting framework are reported here on 4 tables (Table 1-4).

178

179 a) Disease phenotype and features supporting the diagnosis

180 The initiative aimed not to discuss axSpA diagnosis but to describe past and present
181 clinical/biological/imaging features optimally (see Table 1).

182

183 b) Disease Activity:

184 The term "activity" refers to inflammation. For axial involvement, reporting both BASDAI
185 (Bath Ankylosing Spondylitis Disease Activity Index) score and CRP (C-reactive Protein), as
186 well as the ASDAS score (Ankylosing Spondylitis Disease Activity Score) recommended by
187 international and national societies, was confirmed [17]. Additional items suggested include
188 the presence/absence of nocturnal back pain, a specific tool for morning stiffness, and, for
189 extra-spinal manifestations, a simple "yes or no" approach for synovitis, enthesitis, dactylitis,
190 uveitis, inflammatory bowel disease (IBD), and psoriasis. Investigations beyond CRP, such as
191 MRI (magnetic resonance imaging) [18] and ultrasonography, should be mentioned.

192

193

194 c) Disease Severity:

195 The term "severity" refers to irreversible structural damage. This section includes four sub-
196 sections: 1) interview of the patient, 2) self-administered questionnaires, 3) physical exam,
197 and 4) imaging.

198

199 d) Treatments

200 This section is divided into two sub-sections. The first focuses on previously received
201 treatments, with particular attention to non-steroidal anti-inflammatory drugs (NSAIDs),
202 disease-modifying antirheumatic drugs (DMARDs), and physiotherapy (see Table 1). The
203 second covers the current intake of both pharmacological and non-pharmacological
204 modalities. As recommended in a prior RER initiative [8], treatment adherence is evaluated
205 through a simple open question.

206

207

208 **Comorbidity reporting (Table 2)**

209 The group focused on seven specific sections: cardiovascular diseases, infections,
210 malignancies, osteoporosis, gastrointestinal diseases, psychiatric and psychological
211 disorders, and a section dedicated to fibromyalgia. Most items and tools for optimal
212 evaluation were identified in a previous RER initiative [9] and included in EULAR
213 recommendations [19]. Additional comorbidities, including thromboembolism risk,
214 metabolic syndrome, fibromyalgia, anxiety and depression, gastrointestinal diseases, and the
215 use of urine test strips, were discussed during the expert meeting. The use of SCORE2
216 (Systematic COronary Risk Evaluation) and SCORE2-OP (older persons) for cardiovascular risk

217 estimation [20] was discussed, and after a vote session, both items were selected by the
218 experts. However, the collection of the history of fungal infection and urine test strip
219 information was not retained in the report frame. The experts also decided to collect COVID-
220 19 vaccination data but not the date of the last infection.

221

222

223 **Lifestyle and quality of life (Table 3)**

224 Most outcomes in this domain were not discussed in previous RER initiatives or
225 recommendations. All were discussed during workshops and voted on if consensus was not
226 obtained. For physical activity evaluation [21], two scores, IPAQ (international physical
227 activity score) and Ricci and Gagnon [22, 23], were discussed. Although the latter has not
228 been validated, it was recommended by the French National Health Assurance due to its
229 ease of use for patients. The collection of the number of steps per day through a mobile app
230 or connected device was discussed but not retained for the standardized form. For quality-
231 of-life assessment, experts recommended using ASAS-Health Index (ASAS-HI) [24] and the
232 question 1 of BASDAI to assess fatigue. This outcome is used to identify potential sleep
233 apnoea syndrome if the score is > 5/10.

234

235

236 **Digital tools to inform patients about the disease, treatments, self-evaluation and self- 237 management (Table 4).**

238 Following a systematic review of Rheumatology Society, Patient Associations, and Health
239 Authorities websites, as well as Apple Store, Play Store, and YouTube, several websites and
240 apps useful for patients were selected (Table 4). The selection criteria included content, data

241 security, medically controlled information source, and absence of charges for the patient.

242 None of the axSpA-focused videos on YouTube were considered relevant for systematic

243 patient advice.

244

245

246 **Discussion**

247 Through an evidence-based approach followed by expert consensus, this study advances the
248 adaptation of ASAS standard quality of care recommendations for ax-SpA [7] to a national
249 context. It provides a clear definition of what needs to be systematically reported during a
250 holistic evaluation by a rheumatology team. The pragmatic document developed as a
251 reporting framework can prove valuable in both hospital and private clinic settings for
252 rheumatology teams in daily practice.

253 The first part of the evaluation focuses on disease evaluation, encompassing a substantial
254 portion of the work conducted in a previous RER initiative. While building upon prior efforts,
255 the experts proposed adaptations. Notably, all answers to every question of the BASDAI are
256 now collected. The reporting of peripheral and extra-rheumatologic features has been
257 clarified, including the collection of the BASFI and additional imaging modalities, such as
258 peripheral joint radiographs, if available. Moreover, specifics on collecting data regarding
259 NSAIDs consumption and DMARD use have been clarified in the standardized report.
260 Furthermore, the scientific committee proposed to assess separately the domains “disease
261 activity (reflecting the inflammatory process) and the domain “disease severity” (reflecting
262 the irreversible structural damage). For this latter we propose to use self-reported
263 questionnaires such as BASFI and also metrology assessments. However, we have to
264 acknowledge that disease activity might have an impact on these outcomes, especially at an
265 early stage of the disease.

266 The second part of the evaluation focuses on comorbidity evaluation. Building on a previous
267 RER initiative and EULAR recommendations, experts proposed additions to the collection of
268 comorbidities, including sleep apnea syndrome, metabolic syndrome, and non-alcoholic fatty
269 liver disease due to their prevalence in this population. COVID-19 vaccination data were also

270 added. The experts introduced screening for associated fibromyalgia using the Fibromyalgia
271 Rapid Screening Tool (FiRST) questionnaire, emphasizing its association with the disease, its
272 impact on treatment failure, and its ease of detection. However, it should be emphasized
273 that a patient with an active disease might have a false positive test since it has been
274 previously reported that the percentage patients with a positive test for fibromyalgia (FiRST)
275 decreased dramatically after biologic therapy [25] suggesting that this screening should be
276 performed ideally in a patient with a stable non inflammatory stage of the disease.
277 Additionally, screening for anxiety and depression using a simple open question was
278 recommended to account for psychological factors influencing disease activity assessment.

279 The third part of the evaluation focuses on lifestyle and quality of life. Despite the
280 acknowledged need for this evaluation by ASAS and EULAR recommendations [7, 11], a
281 consensus on collecting and reporting this information is lacking. In selecting outcomes,
282 recommendations from Health Authorities and other specialties were considered. For
283 physical activity assessment, the Ricci et Gagnon questionnaire was chosen over the IPAQ
284 [22, 23] due to its ease of use and endorsement by the French National Health Assurance.
285 The use of ASAS-HI [24] was debated, but experts deemed it useful and justified for routine
286 practice.

287 A notable aspect of this initiative is the introduction of numeric tools to support patient
288 information. A systematic search, guided by EULAR recommendations [12] and quality
289 criteria, revealed a scarcity of identified numeric tools. This highlights an unmet need for
290 easily accessible video support for patients in this field.

291 Systematic screenings by multidisciplinary teams have been found to be useful for patients
292 in other chronic disease. For example, a meta-analysis [26] demonstrated that a
293 multidisciplinary team including pharmacists could decrease the rate of hospitalization in

294 patients with chronic heart failure. Another meta-analysis showed that such multidisciplinary
295 teams can reduce the mortality rate in kidney failure [27]. Another meta-analysis [28]
296 showed that a multidisciplinary team could reduce the amputation rate in patients with type
297 2 diabetes foot ulcers. In rheumatology field, a randomized controlled trial in rheumatoid
298 arthritis showed that after a systematic nurse-led screening of comorbidities the
299 management of comorbidities was suboptimal but improved after 3 years [29]. In another
300 randomized trial in ax-SpA, the comorbidity nurse-led screening improved vaccination rate,
301 cancer screening, and osteoporosis management [3]. However, a larger screening
302 multidisciplinary-led program assessing the disease activity and severity, the comorbidities
303 but also other components of the disease, such as impact on quality of life, work, sexuality
304 or future projects have never been evaluated.

305 One strength of the methodology used is the combination of evidence-based and consensus
306 approaches with a representative panel of rheumatologists. However, the absence of
307 available evidence for how outcomes should be collected represents a limitation, mitigated
308 by expert discussions and votes to obtain consensus. The lack of involvement of other health
309 professionals, such as physiotherapists, psychologists, or nutritionists during the expert
310 meeting, could be considered a limitation, as their perspectives might have enriched the
311 discussions.

312 Finally, it should be emphasized that the complete evaluation as proposed in this document
313 is time consuming and not feasible in the daily clinical practice of a rheumatologist.

314 Moreover, this evaluation necessitates ideally the participation of several health professionals.

315 We have to admit that its implementation will depend on the local possibilities in a specific
316 environment (e.g. one day hospital, program implemented by a rheumatology clinical
317 nurse,...).

318 In summary, this initiative, using an evidence and consensus-based process, proposes a
319 standardized report for the global assessment of axial SpA in all its components. This
320 document holds potential for use in daily practice in both hospital-based and private office-
321 based daily practice to standardize disease assessments. Further studies are warranted to
322 assess the feasibility, benefits for patients and health professionals, and the medico-
323 economic evaluation of its implementation in daily practice.

324

325

326

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428

429 Table 1: list of the outcomes to be collected in the standardized form for a global evaluation
 430 of axSpA : disease evaluation domain.

Selected outcomes	Way of reporting	Mode of selection
Disease phenotype		
Axial phenotype (with or without radiographic sacroiliitis)	Yes/no	Scientific committee
Peripheral phenotype (arthritis, enthesitis, dactylitis)	Yes/no	Scientific committee
Extra-articular features (psoriasis, uveitis, IBD)	Yes/no	Scientific committee
Features and exams supporting the diagnosis		
Features: inflammatory back pain, NSAIDs efficacy, history of peripheral and/or extra-rheumatologic features.	Yes/no	Scientific committee
Familial history of axSpA, psoriasis, IBD or uveitis	Yes/no	Scientific committee
Laboratory tests: abnormal CRP, HLA-B27	Yes/no/not available, date of the test, results	Scientific committee
Sacroiliitis on imaging: on radiographs, on MRI	Yes/no/not available, if yes: date and results	Scientific committee
Sacroiliitis on other imaging modalities (yes, no, not available, if yes date and results)	Yes/no/not available, if yes: date and results	Workshop consensus
Disease activity		
Patient questionnaires: Patient Global VAS, ASDAS-CRP BASDAI	Global score Global score and results of each question	Scientific committee Workshop consensus
Interview Nocturnal back Morning stiffness	Yes/no Q5 and Q6 from BASDAI	Scientific committee Workshop consensus
Physical exam: SJC, enthesitis, dactylitis Anterior chest wall pain TJC	Yes/no and localisation Yes/no Yes/no and localisation	Workshop consensus Workshop consensus Votes (n=25, 68%)
Extra-rheumatologic features: Uveitis Abdominal features	Yes/no, number/year To be reported in case and in absence of history of IBD	Workshop consensus Votes (in case of IBD: n=34, 92%, in absence of IBD: n=30, 83%)
Psoriasis presence	Yes/no and localisations: skin, nail and genital	Votes (n=25, 68%)
Other extra-articular	Yes/no, specify	Workshop consensus

Laboratory tests: CRP	Value, date	Scientific committee
Other exams assessing disease activity (for example ultrasound, MRI, ...)	If yes, specify	Workshop consensus
Disease severity		
Interview History of surgery for the SpA Aids or devices used for SpA Severe extra-rheumatologic features ¹	Yes/no, specify Yes/no, specify Yes/no, specify	Workshop consensus Workshop consensus Workshop consensus
Patient questionnaire BASFI	Global score	Votes (n=25, 68%)
Physical exam Occiput-wall distance, Modified Schober, Lumbar lateral flexion, Chest expansion, Finger-floor distance, Chin-manubrium distance Cervical rotation, Coxo-femoral rotations Height loss	Centimetres Degrees Height at 20 years old and current height (cm).	Scientific committee Scientific committee Workshop consensus
Imaging Axial involvement: pelvis and spine conventional radiographs Peripheral involvement: articular conventional radiographs	Yes/no, not available, if yes date and results Yes/no, not available, if yes localisation, date and results	Workshop consensus Workshop consensus
Therapeutic history		
NSAIDS use history	Number of NSAIDs, name of the NSDAIDs, and for each NSAID: efficacy (yes/no), reason of interruption, duration of intake.	Votes (n=30, 81%).
DMARD use history	Number of DMARDs, names of the DMARDs and for each DMARDs specify posology, mode of administration, efficacy (yes/no), dates of use (start, end or on going), if interruption specify why.	Votes (n=35, 94%).
Physiotherapy use	Yes/no	Votes (n=35, 94%).
Current treatment		
NSAIDs	Current NSAID consumption: number of days with at least one intake during the last week	Workshop consensus
DMARDs	Current DMARD, name, posology, mode of administration. Date of start	Workshop consensus Workshop consensus
Treatment side effects	Yes/no, specify	Workshop consensus
Treatment adherence	Open question	Votes (n=33, 91%)

431 IBD: inflammatory bowel disease, NSAIDs: non-steroidal anti-inflammatory drugs, CRP: C-reactive
432 protein, VAS: visual analogic scale, ASDAS-CRP: Ankylosing Spondylitis Disease Activity Score, BASDAI:

433 Bath Ankylosing Spondylitis Disease Activity Index, SJC: swollen joint count, TJC: tender joint count,
434 MRI: magnetic resonance imaging, SpA: spondyloarthritis, BASFI: Bath Ankylosing Spondylitis
435 Functional Index, NSAIDs: non-steroidal anti-inflammatory drugs, DMARD: disease-modifying anti-
436 rheumatic drugs
437 1:feature leading to an irreversible damage (for example fistula in case of Crohn disease,
438 permanent loss of visual acuity in case of uveitis).
439

440

441 Table 2: list of the outcomes to be collected in the standardized form for a global evaluation
 442 of axSpA : comorbidity evaluation domain.

Selected outcomes	Way of reporting	Mode of selection
Cardiovascular comorbidities		
History of: Heart attack/ Angina pectoris/coronary artery disease	Yes/no	Scientific committee
Stroke	Yes/no	Scientific committee
Hear failure	Yes/no	Scientific committee
Peripheral arterial disease	Yes/no	Scientific committee
Cardiovascular risk estimation	SCORE2 and SCORE2-OP	Workshop consensus
Thromboembolism disease	Yes/no	Workshop consensus
Anticoagulant or antiplatelet therapies	Yes/no	Workshop consensus
Cardiovascular risk factors	Yes/no, if yes: treatment, for everybody:	Scientific committee
Hypertension	blood pressure measure	
Diabetes	Yes/no, if yes treatment and HbA1C measure, for everybody: fasting blood sugar	Scientific committee
Dyslipidemia	Yes/no, if yes: treatment. For everybody: LDL-cholesterol and Total cholesterol-HDL cholesterol	Scientific committee Workshop consensus
Obesity	Weight and body mass index	Scientific committee
Smoking	Current smoker/past smoker (< or > 1 year) /never smoke	Workshop consensus
Kidney failure	Glomerular filtration rate	Scientific committee
Familial history of cardiovascular disease	Yes/no	Workshop consensus
Sleep apnoea syndrome	Yes/no, if yes: use of a device? If no: in case of fatigue VAS>5/10, use of STOP-BANG test	Workshop consensus Votes (n=39, 94%)
Metabolic syndrome	Waist circumference. If >94cm in men and 80cm in women, then check other features of metabolic syndrome (triglycerides, HDL-cholesterol, blood pressure and fasting blood sugar).	Votes (n=37, 100%)
Non-alcoholic fatty liver disease	Score FIB-4 in case of metabolic syndrome or hepatic cytolysis	Votes (n=30, 82%)
Infectious comorbidities		
History of: Severe infection	Yes/no, dates	Scientific committee
Non severe repeated infections	Yes/no, localisations	Scientific committee
Chronic bronchitis	Yes/no	Scientific committee
Tuberculosis	History of tuberculosis (yes/no, if yes: date, treatment), tuberculosis contact (yes/no, if yes, date) QuantiFERON	Scientific committee

Viral infections: HIV, HBV, HCV	(yes/no, date, if yes: prophylactic treatment).	Scientific committee
Herpes simplex or zoster infection	For each: yes/no, screening test, results, date	Scientific committee
Dentist visit	Yes/no, if yes: date Date of the last visit	Scientific committee
Vaccination status for		
Diphtheria-Tetanus-Poliomyelitis	Yes/no, date of vaccination or refusal	Scientific committee
Influenza	Yes/no, date of vaccination or refusal	Scientific committee
Pneumococcus	Yes/no, date of vaccination or refusal	Scientific committee
Hepatitis B	Yes/no, date of vaccination or refusal	Scientific committee
Herpes zoster	Yes/no, date of vaccination or refusal	Scientific committee
Papillomavirus	Yes/no, date of vaccination or refusal	Scientific committee
Tuberculosis	Yes/no, date of vaccination or refusal	Scientific committee
COVID-19	Yes/no, date of vaccination or refusal	Workshop consensus
Malignancy comorbidities		
History of malignancy	Yes/no, if yes specify	Scientific committee
Specific malignancy risk evaluation		
Breast	Family history and mammography	Scientific committee
Cervix	Cervical smear	Scientific committee
Prostate	Symptoms or risk factors (family history or ethnic risk – Afro-Caribbean origin): yes/no	Scientific committee
Lung	Smoking yes/no	Scientific committee
Colo-rectal	Faecal immunochemical test, risk factors (inflammatory bowel disease, polyps, family history): yes/no	Scientific committee
Skin	Dermatologist visit: yes/no, if yes: date. Risk factors (fair-skinned, high number of naevi, exposure to PUVA therapy): yes/no	Scientific committee Votes (n=22, 60%)
Lymphoma	Adenopathy clinical examination	Votes (n=23, 62%)
Osteoporosis		
History of osteoporosis	Yes/no, if yes treatment	Scientific committee
History of fractures	Yes/no, if yes specify	Scientific committee
Osteoporosis risk evaluation	Bone mineral density: yes/no, results and date FRAX calculation (only if age ≥ 40 years, T-Score > -3 and risk factor presence)	Scientific committee Votes (n=26, 71%)
Fibromyalgia		
Fibromyalgia screening	FIRST questionnaire	Workshop consensus
Gastrointestinal diseases		
Peptic ulcer	History of peptic ulcer: yes/no Risk factors of peptic ulcers (age ≥ 65 years, anti-platelet treatment, anti-coagulant treatment, NSAID of	Workshop consensus Vote (n=29, 78%)

	glucocorticoid use, Helicobacter Piloni history): yes/no	
Psychiatric comorbidities		
Anxiety or depression	With an open question	Workshop consensus

443 SCORE: Systematic COronary Risk Evaluation, SCORE-OP: Older Persons, STOP-BANG: Sleep Apnea
444 Questionnaire, FIB-4: Fibrosis-4 index, FRAX: Fracture Risk Assessment Tool, FiRST: Fibromyalgia
445 Rapid Screening Tool
446

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448 Table 3: list of the outcomes to be collected in the standardized form for a global evaluation
 449 of ax-SpA : lifestyle and quality of life evaluation domain.

Selected outcomes	Way of reporting	Mode of selection
Lifestyle information		
Familial status	Marital status, number of children	Workshop consensus
Toxic use: Smoking	Never/Current/Past (date of end), smoking consumption in pack-years	Workshop consensus
Alcohol	Yes, < or > 2 drinks/day	Votes (n=37, 100%)
Other toxics	Yes/No, specify	Votes (n=32, 87%)
Physical activity	Ricci and Gagnon score	Votes (n=35, 95%)
Work and social aids	100% coverage assurance: yes/no Work occupation Work status (working, retirement, unemployment). Other information about work occupation, specify. Number of working days lost because of the disease	Workshop consensus Workshop consensus Workshop consensus Votes (n=29, 79%) Votes (n=29, 79%)
Diet	Specific diet: yes/no, if yes specify	Workshop consensus
Quality of life		
Global quality of life	ASAS-HI	Votes (n=20, 55%)
Fatigue	Q1 of BASDAI	Workshop consensus
Intimacy issues	Open question	Votes (n=24, 66%)
Work difficulties	Open question	Votes (n=26, 71%)
Future projects		
Desire for parenthood	Open question	Workshop consensus
Travel plans	Open question	Workshop consensus

450 ASAS-HI: Assessment of SpondyloArthritis International Society; Q1 of BASDAI: first question of the
 451 Bath Ankylosing Spondylitis Disease Activity Index
 452

453 Table 4: Numeric tools that could be advised to axSpA patients.

Selected outcomes	Source	Mode of selection
Websites recommended for information about the disease		
Ameli.fr Société Française de rhumatologie Spondyloarthrite en 100 questions Patient associations	www.ameli.fr https://public.larhumatologie.fr https://www.rhumatismes.net/index.php?id_bro=29 List of the patient's associations available on "Spondyloarthrite en 100 questions"	Workshop consensus Workshop consensus Workshop consensus Votes (n=31, 84%)
Mobile app recommended for self-management or self-evaluation		
Self-management Of the treatments Of back pain Activ'Dos Self-evaluation of physical activity	Hiboot® (http://www.hiboot.fr/) Activ'Dos (https://www.ameli.fr) Number of step/days from a step tracker (from the mobile phone or a connected wristband or watch, without specifying a brand).	Workshop consensus Workshop consensus Votes (n=37, 100%)

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