



# Elevating the Standard of Care for Patients with Axial Spondyloarthritis: ‘Calls to Action’ from Rheumacensus, a Multistakeholder Pan-European Initiative

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## ABSTRACT

**Introduction:** Several barriers to optimal care in axial spondyloarthritis (axSpA) exist, which is detrimental to patient outcomes. The Rheumacensus programme aimed to identify how the standard of care (SoC) and treatment ambition for patients with axSpA could be elevated, from

the unique perspective of three key stakeholders from across Europe: patients, healthcare professionals (HCPs) and payors.

**Methods:** Rheumacensus followed three phases: an insights-gathering workshop to identify current unmet needs in axSpA and an area of focus, a modified Delphi process to gain consensus on improvements within the agreed area

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of focus, and a Consensus Council (CC) meeting to generate ‘Calls to Action’ (CTA) to highlight the changes needed to elevate the SoC for patients with axSpA.

**Results:** The Rheumacensus CC consisted of four patient representatives, four HCPs and four payors. All 12 members completed all three Delphi e-consultations. The shared area of focus that informed the Delphi process was patient empowerment through education on the disease and treatment options available, to enable patient involvement in management and ultimately increase treatment adherence. Four key themes emerged from the Delphi process: patient empowerment, patient knowledge, patient–HCP consultations and optimal initial treatment. These themes informed 11 overarching CTA, which demonstrate the need for a multistakeholder approach to implement a paradigm shift towards patient-centred care to elevate health outcomes in patients with axSpA.

**Conclusion:** Rheumacensus identified CTA to help bridge the disparities observed in axSpA care. It is now imperative for all stakeholders to take practical steps towards addressing these CTA to elevate the SoC and treatment ambition in patients with axSpA.

and poor disease management. This report is about a programme called Rheumacensus which has the overall aim of improving the standard of care (SoC) for patients with axSpA. Rheumacensus brings together the points of view of three key groups involved in the care of people with axSpA: patients, payors and healthcare professionals (HCPs) from across Europe. Together, these three groups agreed to focus on patient empowerment through education on the disease and treatment options to effectively enhance treatment adherence, as a way to raise the SoC. Through a series of exercises—to agree on the current SoC and what needs to be improved—and group discussions, four themes were established which were used by the groups to help them suggest ‘Calls to action’ (CTA). The CTAs were ideas of how improvements could be made or what needs to be done to improve the care patients receive. The four themes were (1) patient empowerment, (2) patient knowledge, (3) patient–HCP consultation and (4) optimal initial treatment. In total, 11 CTAs were developed across these themes that provide direction and practical next steps which patients, payors and HCPs could take to drive change and make a real difference to patients by improving their care.

## PLAIN LANGUAGE SUMMARY

Axial spondyloarthritis (axSpA) is a long-term inflammatory disease involving the spine and other joints of the body as well as where tendons and ligaments attach to bone. AxSpA is associated with a significant burden to patients which can be worsened by delays in diagnosis

**Keywords:** Axial spondyloarthritis; Consensus; Standard of care; European; Multistakeholder; Patient-centric care

### Key Summary Points

Several barriers to best practice care in axial spondyloarthritis (axSpA) exist, preventing patients from achieving optimal outcomes. Rheumacensus is a multidisciplinary, pan-European initiative involving 12 stakeholders evenly representing three key stakeholder groups: patients, healthcare professionals (HCPs) and payors.

Stakeholder leads identified a shared area of focus which informed the rest of the programme: *patient empowerment through education on the disease and treatment options available, to enable patient involvement in management and ultimately increase treatment adherence.*

A modified Delphi process was used to gain multistakeholder consensus on statements based on insights around the shared area of focus, giving rise to four areas of management requiring improvement (themes): patient empowerment, patient knowledge, patient–HCP consultations and optimal initial treatment.

Consensus statements were used to inspire ‘Calls to Action’ per theme, designed to bridge the gap between the current and desired care which, if implemented, would contribute to an elevation in the standard of care for patients with axSpA.

The key areas of action that require change in axSpA care focused on many aspects of patient empowerment, including the need for effective communication, collaboration and education between stakeholders, as well as increased awareness of patient rights, personalised care and treatment access.

## INTRODUCTION

Axial spondyloarthritis (axSpA) is a complex chronic inflammatory disease that affects the axial skeleton, comprising both radiographic and non-radiographic forms [1–5]. Clinical manifestations include progressive back pain, morning stiffness, fatigue, functional impairment and often irreversible structural damage of the axial skeleton [1, 2]. Several barriers to optimal care exist e.g. identification and timely referral of patients with axSpA [3, 6, 7]. Lack of axSpA awareness and knowledge, coupled with the insidious onset of symptoms may contribute to these barriers [6–8].

In Europe, patients with axSpA experience an average diagnostic delay of 5–7 years, prolonging the initiation of optimal treatment, which is associated with high healthcare resource utilisation from many visits to healthcare professionals (HCPs) and the cost of inappropriate treatments [8–12]. Indirect costs related to days of absence from work can also be associated with diagnostic delay [12].

Peripheral (arthritis, enthesitis, dactylitis) and extra-musculoskeletal (uveitis, psoriasis, inflammatory bowel disease) manifestations are common in patients with axSpA as a result of shared risk factors, consequences of inflammation, or side effects of long-term axSpA treatment (e.g. non-steroidal anti-inflammatory drugs) [2, 3, 5, 13]. Many patients with axSpA have at least one comorbidity, the most common being hypertension, hyperlipidaemia and obesity [5]. The broad physical, social and psychological impact on patients with axSpA creates a cumulative burden, negatively affecting health-related quality of life (HR-QoL), work productivity, social functioning, and psychological health [1, 2, 5]. Therefore, a multidisciplinary approach is needed to optimise care, but this varies in the clinic and feasibility (e.g. human resources, administrative burden and economic cost) is not well defined [14].

Disparities exist around treatment goals of HCPs and patients, causing patients to feel unsupported and undervalued [1, 2]. However, in recent years a shift towards patient-centred care is advocating for patient involvement in

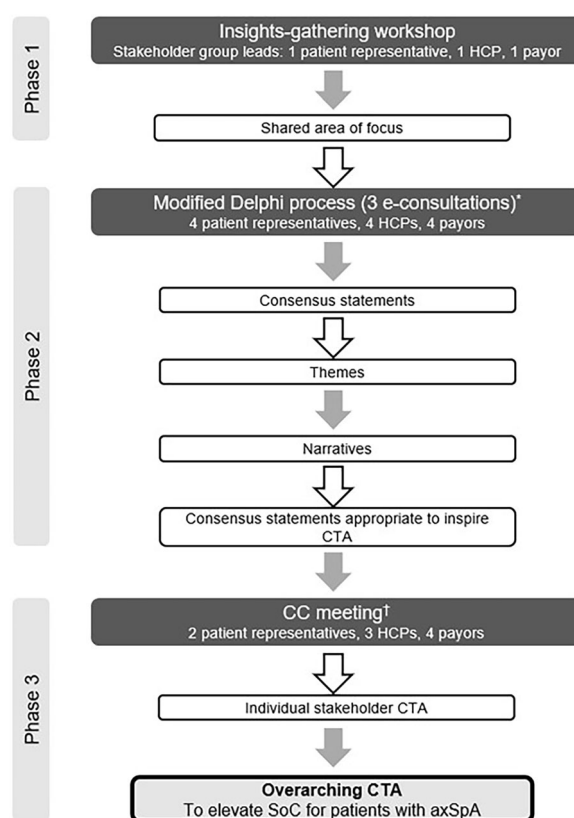
shared decision-making (SDM) [5, 7, 13, 15]. Inadequate insurance coverage, lack of awareness around treatment options and limited patient education on treatment (e.g. risks and benefits) also limit care [7]. Therefore, a holistic approach between HCPs, payors and patients is essential to promote patient empowerment and elevate health outcomes [1, 2, 5, 13, 15]. Nonetheless, lack of available resources and outdated attitudes limit implementation in practice [5, 15].

The Rheumacensus programme is unique as it aims to explore different ways in which the standard of care (SoC) and treatment ambition for patients with axSpA could be elevated, from the perspective of three important stakeholders: patients, HCPs and payors. Herein, we describe this programme that was initiated to gain

consensus on the current SoC in axSpA via a Delphi process, identify potential improvements and inspire ‘Calls to Action’ (CTA) to drive key stakeholders to elevate axSpA care, contributing to the long-term improvement in HR-QoL.

## METHODS

The Rheumacensus programme is a multistakeholder initiative combining participants from different European countries, to identify challenges in the current management of psoriatic arthritis (PsA) and axSpA and generate CTA which, if addressed, can contribute to an improvement in the overall SoC for patients with these conditions (Fig. 1). The results of the



**Fig. 1** Process of the Rheumacensus axSpA programme. \*Twelve participants were recruited and contracted; four were female and eight were male. All 12 CC participants completed all three Delphi e-consultations. †One HCP and two patient representatives were unable to attend the

meeting but provided their CTA after the meeting. *axSpA* axial spondyloarthritis, *CC* Consensus Council, *CTA* ‘Calls to Action’, *HCP* healthcare professional, *SoC* standard of care.

PsA workstream are published elsewhere [<https://doi.org/10.1007/s40744-024-00664-3>].

Twelve experts with a prominent level of engagement and experience in axSpA (e.g. those involved in clinical trials, authors of manuscripts on axSpA, those who treat patients with axSpA, are involved in funding axSpA medications, are a member of a patient organisation or a patient with axSpA) were recruited to participate in the axSpA Rheumacensus Consensus Council (CC) from a range of different countries across Europe. The CC consisted of three equally represented stakeholder groups: HCPs (clinicians, nurses, physiotherapists), payors and patient representatives, each with a nominated group lead (Table 1). The aim was to ensure diversity with panellists from different countries and healthcare systems and equal representation of gender as far as possible while recruiting experts with adequate experience of axSpA to contribute to the programme.

There was no need to collect any type of patient data. Hence, the approval of an ethics committee was not required. Consent was obtained from all axSpA CC members as they were contracted by UCB Pharma to take part in this programme.

A virtual stakeholder leads workshop was held in June 2022 (via Zoom) to gather insights into unmet needs in the management of axSpA from all stakeholder perspectives (Table S1). The stakeholder leads were asked in turn what unmet needs they encounter in axSpA care and what the challenges and barriers are to elevating the SoC for patients with axSpA. The unmet needs were captured, and all stakeholders discussed which unmet needs should be prioritised through Rheumacensus to make the greatest improvement to the current SoC. Discussion revealed that the common thread across the stakeholder groups that underpinned most of the identified needs was patient empowerment and the need for personalised care. The shared area of focus was refined and agreed by all the stakeholder leads—*patient empowerment through education on the disease and treatment options available, to enable patient involvement in management and ultimately increase treatment adherence*.

A modified Delphi method was used to explore the shared area of focus of patient empowerment from the perspective of all three stakeholders with the aim of gaining consensus across stakeholders on the current state of patient empowerment, the need for change and the desired state/action. Three rounds of Delphi e-consultations were distributed to all participants to complete anonymously via Microsoft Forms between September 2022 and January 2023. These were comprised of statements with multiple-choice answers for level of agreement (strongly agree, agree, disagree, or strongly disagree) to assess consensus (defined as more than or equal to 75% of participants selecting ‘agree’ or ‘strongly agree’), and ‘complete the sentence’ and free-text questions to gather further insights. Each successive Delphi round was refined on the basis of feedback from participants from the previous round. All 12 members of the CC took part in this process and completed all three rounds of the Delphi.

Following the Delphi e-consultations, four themes were identified: patient empowerment, patient knowledge, patient–HCP consultations and optimal initial treatment that related to different aspects of the focus area. Overarching narratives were then created, one per theme, by further distilling the statements into the insights they provided relating to the current situation, the need for change and desired state/action. This was done to summarise the outcome of the Delphi process to set the scene for the CC meeting where key consensus statements that reflected the desired state/action were used to inspire CTA. Not all statements that achieved consensus were needed in the narratives. Statements were omitted if they did not add further detail to the narrative to ensure narratives were concise. Statements were also omitted from the narratives if they specifically related to how a change should be implemented and so will be considered when the Rheumacensus programme moves into the implementation stage. The purpose of the CC meeting was to generate CTA—practical ideas that if addressed through the implementation of novel initiatives would contribute to an elevation in the SoC of patients with axSpA.

**Table 1** Members of the axSpA Rheumacensus CC

CC members	Background	Country
HCPs		
Xenofon Baraliakos (group lead)	Medical Director, The Rheumatism Centre in the Ruhr Area, Herne	Germany
Cristina Fernández-Carballido	Consultant Rheumatologist, University Hospital San Juan de Alicante, Alicante	Spain
Ennio Lubrano	Full Professor of Rheumatology, Department of Medicine and Health Sciences and Head of the Internal Medicine and Rheumatology Unit, University of Molise	Italy
Fiona Wilson*	Chartered Physiotherapist and Associate Professor, School of Medicine, Trinity College Dublin	Ireland
Payors		
Bart J.F. van den Bemt (group lead)	Professor of Personalised Pharmaceutical Care, Radboud University Medical Centre	The Netherlands
Detlev Parow	Formerly Department of Medicines, Therapeutic Appliances and Remedies, DAK-Gesundheit, Hamburg	Germany
Pavel Mlynar	CPZP	Czech Republic
Inderjit Singh	Chief Pharmacist, University Hospitals, Birmingham	UK
Patient representatives		
Andri Phoka (group lead)	Secretary of ASIF	Cyprus
Fabienne Lacombe*	Director of AFS	France
Silvia Tonolo*	President of ANMAR	Italy
Dale Webb	Chief Executive, National Axial Spondyloarthritis Society	UK

\*Participants who were absent from the virtual CC meeting and provided their CTA after the meeting  
*ANMAR* National Association of Rheumatic Patients, *AFS* The France Spondyloarthritis Association, *ASIF* Axial Spondyloarthritis International Federation, *axSpA* axial spondyloarthritis, *CC* Consensus Council, *CPZP* Czech Industrial Health Insurance Company, *CTA* ‘Calls to Action’, *HCP* healthcare professional, *UK* United Kingdom

The virtual CC meeting was held via Zoom in March 2023. The meeting lasted 3.5 hours and was attended by nine of the 12 CC members. For each theme in turn, the narrative was presented, then consensus statements that described the desired SoC were used to stimulate the generation of CTA. This was done in breakout rooms to separate participants into their respective stakeholder groups (patient

representatives, HCPs, payors). Participants then proposed and discussed CTA based on what they must do to address the statements presented. Then each stakeholder group presented their ideas to all the CC members so they could be discussed. Participants who were unable to attend were provided with a workmat containing an example CTA to complete and return via email to ensure their ideas were



captured. Following the meeting, overarching CTA that all stakeholders could play a part in addressing were generated and agreed by the CC members (Fig. 1).

## RESULTS

### Shared Area of Focus

The stakeholder leads workshop identified a shared area of focus in axSpA which informed the rest of the programme—*patient empowerment through education on the disease and treatment options available, to enable patient involvement in management and ultimately increase treatment adherence*. See supplementary materials (Table S1) for more information.

### Participants

Participants of the axSpA CC were recruited on the basis of their expertise and experience in axSpA (Fig. 1, Table 1).

### Themes and Narratives

Following the Delphi process, four key themes emerged that the consensus statements could be divided into.

#### 1. Patient Empowerment

##### **Discussion Points**

After completion of the Delphi process, 21 statements reached consensus, of which 16 were used in the patient empowerment narrative (Tables 2, S2).

Patient empowerment was defined as “the process by which people are supported to gain sufficient knowledge and skills, to enable them to be as actively involved as they want to be in making decisions that shape their health”. The initial definition was modified as stakeholders felt that knowledge alone was insufficient to empower patients (Table S2). An empowered patient was described as someone who can confidently discuss and proactively bring up symptoms, treatment options and concerns

with their HCP. While 83% ‘agreed’ or ‘strongly agreed’ that patient empowerment plays a role in patients demanding higher treatment goals, 17% disagreed, explaining that “higher treatment goals” do not reflect patient objectives, as patients simply want to be well and so they focus on maintaining good results rather than prioritising higher goals.

Stakeholders felt the main barriers to patient empowerment are the lack of easily accessible, trustworthy information, reluctance of patients with axSpA to be involved in their care and the paternalistic approach to medicine by HCPs. Consensus was achieved for all stakeholders having a role in empowering patients with axSpA (Table 2). However, those who disagreed with a role for the pharmaceutical industry felt that HCPs had a greater role, as patients may view industry involvement to be solely based around promotion of their products, thus reducing patient confidence in decision-making. Similarly, the role of payors was challenged as a result of potential conflicting interests i.e. favouring lower costs of treatment.

Insights suggested that patient organisations offer support through educational programmes/workshops directed to all stakeholders. However, one stakeholder felt that HCPs obtain information through professional associations and so joint support is not needed. The need for reliable ways of measuring patient empowerment in axSpA reached consensus (Table 2); patient surveys could be used to understand and monitor the extent of patient involvement in disease management.

Fifty-eight percent of stakeholders recognised variations in patient empowerment with ethnicity, where some ethnicities (in particular, Asian and African) have fewer opportunities than others to engage in their care as a result of cultural and socio-economic factors. Table 3 contains the overarching CTA and associated stakeholder-specific discussions for the theme of patient empowerment. Overarching CTA were derived from the CTA specific for each stakeholder group (Tables S3, S4) which were inspired by the consensus statements marked with a superscript dagger symbol in Table 2 and generated at the CC meeting.

**Table 2** Patient empowerment narrative

Narrative		Supporting consensus statements	Percentage agreement
Current situation	Patient empowerment in axSpA is currently suboptimal, particularly for those from poor socio-economic backgrounds and with a low education level	The level of patient empowerment of patients with axSpA is variable but generally low	83%
		There is room for improvement in the level of patient empowerment in axSpA	100%
		Patients with axSpA and a poor socio-economic background and/or low education level have lower levels of empowerment than those with higher socio-economic backgrounds and education levels	92% and 100%*, respectively
Need for change	Empowering patients with axSpA to be involved in their own care will improve communication with HCPs, drive aspiration for higher treatment targets and improve patient outcomes and treatment adherence	The level of empowerment of patients with axSpA influences how HCPs communicate with them	83%
		The level of empowerment of patients with axSpA affects treatment decisions	83%
		Empowering patients with axSpA to be involved in their own care will improve their outcomes and treatment adherence	100% and 100%*, respectively
		Patient empowerment has a role in patients demanding higher treatment targets in axSpA than they previously aspired to <sup>†</sup>	83%
		Self-monitoring of symptoms by patients with axSpA improves their consultations with HCPs	100%



**Table 2** continued

Narrative		Supporting consensus statements	Percentage agreement
Desired state/action	All stakeholders play a key role in empowering patients with axSpA	Patient organisations, HCPs, payors and the pharmaceutical industry have a key role to play in supporting the empowerment of patients with axSpA <sup>†</sup>	100%, 100%, 75% and 75%, respectively*
		One way that pharmaceutical companies could support the empowerment of patients with axSpA is by supporting patient organisations to create and deliver educational programmes for patients	92%
		There is a need for reliable ways of measuring patient empowerment in axSpA <sup>†</sup>	83%

Percentage agreement is the proportion of respondents selecting ‘agree’ or ‘strongly agree’ (other options were ‘disagree’ and ‘strongly disagree’)

*axSpA* axial spondyloarthritis, *CC* Consensus Council, *CTA* ‘Calls to Action’, *HCP* healthcare professional

\*Multiple statements achieving consensus have been merged for brevity in this table; percentages indicate the level of consensus achieved to the individual statements in the Delphi (for individual statements see supplementary materials)

<sup>†</sup>Statements were taken into the CC meeting to inspire CTA per stakeholder group; these statements were chosen as they describe the desired state and changes to axSpA care so form a foundation for generating CTA

## 2. Patient Knowledge

### Discussion Points

Of the 15 statements that achieved consensus, 12 were used in the patient knowledge narrative as they succinctly underpinned the current situation, need for change and desired state/action (Tables 4, S5).

Only 42% of stakeholders agreed that patients with axSpA are sufficiently knowledgeable about their disease. Further insights from the 58% who disagreed revealed that the current information available to patients with axSpA is not patient-friendly, relevant or accessible, and is not clearly understood. Moreover, all stakeholders highlighted that there is room for improvement in the level of knowledge and creating patient-friendly education tailored to their interests is important. The need to understand available treatment options in addition to disease knowledge was

reflected in the revised statement, which included this, reaching 100% consensus (Table S5). All stakeholders advocated the role of exercise in axSpA management (Table 4). However, 8% disagreed that exercise plans should be adhered to as patients have the right to choose. Stakeholders recognised the need for non-judgemental, open discussions between HCPs and patients about adhering to exercise plans.

Open-ended questions about the facilitation of patient empowerment and involvement in care identified important educational topics, e.g. treatment expectations, self-evaluation, comorbidity recognition, influence of lifestyle factors and compliance to treatment plans. All stakeholders voted that patient education should be delivered through face-to-face discussions with their HCP. The use of questionnaires to assess patient knowledge was proposed, while aiming to avoid response bias

**Table 3** Overarching CTA and associated stakeholder-specific discussions for the theme of patient empowerment

No.	Overarching CTA	Stakeholder-specific discussions underpinning each overarching CTA
1.1	Make patients aware of their role and rights in their care and support them to voice their experience, ask questions and state their treatment goals	<p>Patient representatives acknowledged initial concerns patients with axSpA may have in engaging in their care, out of fear of being undervalued or due to difficulties in communicating with HCPs. Therefore, patient representatives noted that it is crucial they support HCPs in how to communicate effectively with patients on an individual level, to aid SDM and encourage higher treatment goals</p> <p>Similarly, HCPs noted the importance of utilising existing initiatives to supplement their learning, draw from the patient voice and empower patients with axSpA</p> <p>Payors identified their role in supporting the development of instruments to explain how patients can engage in their care—from initial consultations through to treatment decisions</p>
1.2	Audit currently available patient empowerment measures and tailor these to individual patient needs before implementation in the clinic	<p>HCPs highlighted their role in investigating if there are any specific or generic patient empowerment tools available to optimise their use in the clinic, whilst patient representatives could help patients understand the ‘what’, ‘when’ and ‘how’ of patient activation</p> <p>Payors supported the co-creation of a patient empowerment ‘quality indicator’ with patient organisations</p> <p>All stakeholders advocated the development of measures that reflect individual patient needs i.e. differences in treatment goals across patient subtypes (e.g. gender, age, comorbidities)</p>

*axSpA* axial spondyloarthritis, *CTA* ‘Call(s) to Action’, *HCP* healthcare professional, *SDM* shared decision-making

(i.e. knowledgeable patients may be more likely to engage in questionnaires than those less knowledgeable). Other means of assessing patient knowledge included patient focus groups led by patient representatives and optimised use of existing tools. Alongside patient education, stakeholders felt that HCPs and payors should be educated on their interpersonal skills and the non-clinical impact of

axSpA (e.g. family planning, emotional well-being, employment).

All stakeholders acknowledged the need for easily accessible, high-quality, neutral information, but recognised support may be needed to help patients understand what constitutes “high-quality” as a large amount of poor-quality information is available (e.g. social media). Fifty percent of stakeholders disagreed that patient

**Table 4** Patient knowledge narrative

Narrative		Supporting consensus statements	Percentage agreement
Current situation	Patient knowledge of axSpA and the treatment options available is suboptimal	There is room for improvement in the level of patient knowledge about axSpA and the treatment options available	100%
		HCPs have the main responsibility for providing patients with axSpA with high-quality education on their disease and the treatment options available but do not always have sufficient time to provide it <sup>†</sup>	92%
Need for change	Lack of knowledge hinders patient's involvement in treatment decisions	A patient with axSpA must be sufficiently knowledgeable about their disease and available interventions to be included in making treatment decisions	83% and 92%*, respectively
		Education of patients with axSpA should be tailored to their capacity to learn and understand	100%
		HCPs are most open to SDM when patients with axSpA show a high level of understanding of their disease and the treatment options available	100%
Desired state/ action	Patients need easily accessible, high-quality, neutral information to be able to improve their knowledge of all aspects of the disease and the treatment options	All patients with axSpA should be given the opportunity and educational materials to learn about their disease and treatment options	100%
		Patients with axSpA need easily accessible, high-quality, neutral information about their disease <sup>†</sup>	100%
		Patients need more high-quality information on how to manage all aspects of axSpA (e.g. relationships, mental health, adverse events, employment, etc.)	100%
		Patients with axSpA should understand the role of exercise in managing their condition	100%
		Patients with axSpA should be directed to patient organisations as sources of high-quality education <sup>†</sup>	83%
		Patients with axSpA need help to identify high-quality information on their disease and the available treatment options <sup>†</sup>	100%

Percentage agreement is the proportion of respondents selecting 'agree' or 'strongly agree' (other options were 'disagree' and 'strongly disagree')

*axSpA* axial spondyloarthritis, *CC* Consensus Council, *CTA* 'Calls to Action', *HCP* healthcare professional, *SDM* shared decision-making  
\*Multiple statements achieving consensus have been merged for brevity in this table; percentages indicate the level of consensus achieved to the individual statements in the Delphi (for individual statements see supplementary materials)

<sup>†</sup>Statements were taken into the CC meeting to inspire CTA per stakeholder group; these statements were chosen as they describe the desired state and changes to axSpA care so form a foundation for generating CTA

**Table 5** Overarching CTA and associated stakeholder-specific discussions for the theme of patient knowledge

No.	Overarching CTA	Stakeholder-specific discussions underpinning each overarching CTA
2.1	Provide patients with bite-sized, interactive, educational resources, tailored to their individual needs, on any aspect of living with axSpA that interests them (including clinical, holistic and health economic topics)	<p>Although HCPs were recognised as having the main responsibility for ensuring patients with axSpA are provided with high-quality education, all stakeholders acknowledged the importance of a multistakeholder approach</p> <p>HCPs recognised that gaps in patient knowledge limit availability of education (i.e. patients do not know what to search for) and so provision of materials covering a wide range of topics can enable patients to access information they may not have initially sought out</p> <p>With the support of patient representatives, payors advocated for enhanced patient education of health economic concepts, terminology, and awareness of treatment availability</p> <p>To increase engagement and uptake of materials, patient representatives suggested the adoption of short-form, interactive resources that can be accessed across different channels</p>
2.2	Forge collaborations between HCPs and patient representatives to co-create, validate, and distribute high-quality information to patients and become the recognised sources of reliable and accessible information	<p>Strong relationships between HCPs and patient representatives are vital for improving patient knowledge in axSpA, as patients often recognise patient organisations as trustworthy sources of information. However, many patients with axSpA are unaware of their existence and how they can support their treatment journey. Therefore, HCPs recognised their role in “bridging the gap” between patients and patient organisations, to encourage involvement and increase access to education</p>

*axSpA* axial spondyloarthritis, *CTA* ‘Call(s) to Action’, *HCP* healthcare professional

organisations should have the main responsibility for ensuring patients have access to high-quality information (Table S5). Payors felt that patient organisations and HCPs should work together to create, provide and explain education, but that ultimate responsibility for patient education lies with HCPs as they are more informed. The revised statement specifying HCPs subsequently achieved consensus, but challenges of implementation in clinical

practice were recognised e.g. HCPs lack time to adequately educate patients (Table 4). Table 5 contains the overarching CTA and associated stakeholder-specific discussions for the theme of patient knowledge. See Tables S6 and S7 in the supplementary materials for the CTA per stakeholder.

### 3. Patient–HCP Consultations

#### *Discussion Points*

Consensus was achieved on 20 statements (Table S8), of which 12 were used within the patient–HCP consultations narrative as they succinctly underpinned the current situation, need for change and desired state/action (Table 6). One statement was also used within the optimal initial treatment narrative, as it shaped both narratives (Table 8).

The patient–HCP narrative focused on patient-centred care and identified the importance of SDM in elevating the SoC in axSpA. Initial disagreement around recognition of the full patient burden by HCPs highlighted one of many challenges faced within axSpA care. Payors felt that HCPs cannot understand the full burden as they do not experience the disease in daily life, highlighting the importance of the patient voice during consultations. Stakeholders felt that current tools do not capture the full disease burden and thus consensus was achieved that HCPs should be educated on the burden of axSpA through patient experience and that patient-reported outcome tools are required. Despite the need for patient involvement, stakeholders agreed that many patients are not aware of their potential involvement in treatment decisions (Table 6). Several stakeholders felt that this was due to the traditional, hierarchical relationship between patients and HCPs, as well as a lack of patient confidence—rather than unwillingness—to take part (Table S8). Consequently, consensus was achieved that patients with axSpA should be made aware of their role in treatment decisions and asked if they would like to be involved (Table 6).

Further insights demonstrated the need for HCPs to facilitate open conversations where patients feel valued. All stakeholders advocated for a personalised approach to treatment (i.e. based on gender, ethnicity, lifestyle factors, presenting disease features) and 92% recognised the need to align HCP and patient goals before proceeding with treatment (Table 6). Initial disagreement was observed over which stakeholder should have the final say in treatment decisions (Table S8). Stakeholders felt that while

it was important to take patient opinions into account to avoid compliance issues, patients may have limited knowledge of clinical considerations or funding restrictions compared with HCPs. Therefore, consensus was reached once the statement was modified to acknowledge that both HCPs and patients should have an equal say and if disagreement remains, further discussions should be had. Although consensus was reached that the main barrier HCPs experience is a lack of time in appointments, those who disagreed suggested that this is a false perception that patient involvement takes time and reflects a reluctance to embrace a patient-centred approach. Table 7 contains the overarching CTA and associated stakeholder-specific discussions for the theme of patient–HCP consultations. See Tables S9–S11 in the supplementary materials for the CTA per stakeholder.

### 4. Optimal Initial Treatment

#### *Discussion Points*

Seven statements achieved consensus and were used within the optimal initial treatment narrative (Table 8, Table S12).

Fifty percent of stakeholders, including payors, agreed that payors are sufficiently educated on axSpA and outcomes of different treatment options but that they are constrained from providing optimal initial care by higher authorities. Payors who disagreed explained that prioritising cost considerations over optimal initial treatment is an outdated belief and, in some countries, (e.g. Germany) there are no major restrictions to prescribing whatever treatment is necessary. Additionally, one payor noted that it is not only healthcare systems that influence optimal treatment but that guidelines created by scientific societies play a role too. Consensus was reached once the initial statement was revised to note that educating payors on the burden of disease and the outcomes of using optimal initial treatments will allow more patients to access the most appropriate biologics to meet their treatment goals (Table S12).

The contrast between cost considerations and personalised treatment was evident and felt to negatively affect treatment decisions and

**Table 6** Patient–HCP consultations narrative

Narrative		Supporting consensus statements	Percentage agreement
Current situation	Many patients are not aware that they can be involved in treatment decisions	Many patients are not aware that they have an option to be involved in treatment decisions	92%
		One of the main barriers that HCPs experience to involving patients with axSpA in treatment decisions is a lack of time in appointments	75%
		One of the main barriers to patients with axSpA being involved in treatment decisions is that some patients lack the confidence to get involved	92%
Need for change	HCP–patient communication is key to ensure treatment decisions are based on a complete picture of the disease burden and tailored to individual patient needs	Treatment choice should be based on the individual needs of each patient with axSpA	100%
		HCPs should ask questions to establish the full burden of axSpA on all aspects of the patient’s life, rather than relying on the patient to proactively volunteer information	100%
		HCPs must make sure that they consider what is important for each patient (e.g. family planning, the ability to continue hobbies, resolution of particular symptoms over others, etc.) before treatment decisions are made	92%
Desired state/action	Patients and HCPs should have an equal say in deciding on which interventions to use and should be aligned on treatment goals	Patients with axSpA should be made aware that they can be involved in treatment decisions and asked if they want to be involved*	100% and 92% <sup>†</sup> , respectively
		HCPs must phrase achievable treatment targets in axSpA in a way that is easy to understand and is relevant to the patient’s life, e.g. being able to do a certain activity	92%
		Patients with axSpA and HCPs must align on treatment goals before deciding on a treatment*	92%
		Patients with axSpA and their HCPs should have an equal say in deciding which interventions to use; if the patient and HCP disagree, efforts should be made to reach a shared decision through further discussion*	83% and 100% <sup>†</sup> , respectively

Percentage agreement is the proportion of respondents selecting ‘agree’ or ‘strongly agree’ (other options were ‘disagree’ and ‘strongly disagree’)

axSpA axial spondyloarthritis, CC Consensus Council, CTA ‘Calls to Action’, HCP healthcare professional

\*Statements were taken into the CC meeting to inspire CTA per stakeholder group; these statements were chosen as they describe the desired state and changes to axSpA care so form a foundation for generating CTA

<sup>†</sup>Multiple statements achieving consensus have been merged for brevity in this table; percentages indicate the level of consensus achieved to the individual statements in the Delphi (for individual statements see supplementary materials)



**Table 7** Overarching CTA and associated stakeholder-specific discussions for the theme of patient–HCP consultations

No.	Overarching CTA	Stakeholder-specific discussions underpinning each overarching CTA
3.1	Support patients to confidently converse with HCPs	Patient representatives acknowledged their role in improving patient–HCP communication by supporting patients to develop effective communication skills, increase their confidence and understand which treatments might be best for them
3.2	Actively listen to the patient’s lived experience of axSpA and take this into account rather than solely using laboratory results/clinical findings to guide management	Additionally, collaborations between rheumatology departments and patient organisations could help facilitate conversations between HCPs and patients by ensuring the patient experience is incorporated throughout conversations  Payers recognised their role in supporting patient preparation for consultations by providing education on what to ask in consultations i.e. around prescribed treatments and related costs
3.3	Collaborate with specialist rheumatology nurses to ascertain patients’ individual needs to inform and set tailored treatment goals	Collaborations between specialist rheumatology nurses and HCPs were advocated to address the lack of time during appointments, enabling patients to have an opportunity to discuss their needs and feel valued  Furthermore, HCPs recognised the need to review and recalibrate treatment goals throughout the patient journey as necessary, ensuring treatment success or failure is openly discussed
3.4	Structure and tailor consultations according to the patient’s agenda to cover all aspects of axSpA management important to each individual patient and reach a shared treatment decision	Patient-centric care can be realised through patients with axSpA setting the agenda for their consultations with HCPs, guided by the support of both HCPs and patient representatives  Unrealistic goals should be appropriately explained to the patient to reach a shared decision  In addition, compatibility between mode of treatment, patient lifestyle and treatment side effects are important factors for both patients and HCPs to discuss  Payers felt they should increase awareness around treatment availability and costs and be open to accepting novel data that go against traditional algorithms and guidelines, to treat patients using a more personalised approach

*axSpA* axial spondyloarthritis, *CTA* ‘Calls to Action’, *HCP* healthcare professional

**Table 8** Optimal initial treatment narrative

Narrative		Supporting consensus statements	Percentage agreement
Current situation	To ensure a cost-effective utilitarian approach, payors prioritise cost considerations of treatments across the axSpA population over individual patient outcomes	Payors prioritise cost considerations of axSpA treatments across the population over individual patient outcomes	75%
Need for change	Although essential for the sustainability of healthcare systems, prioritising cost considerations over optimal initial treatment can be detrimental to patient outcomes	Prioritising cost considerations over optimal initial treatment for patients with axSpA can negatively affect treatment decisions and lead to poor patient outcomes	75% and 83%*, respectively
		Optimal initial treatment on a patient-by-patient basis will result in wider and earlier use of biologics in axSpA	83%
		Educating payors on the burden of disease and the outcomes of using optimal initial treatments will allow more patients to access biologics	83%
Desired state/action	Ideally, all patients would have access to optimal initial treatment based on their individual needs	Treatment choice should be based on the individual needs of each patient with axSpA <sup>†</sup>	100%
		Healthcare systems should be designed to ensure each patient with axSpA can access optimal treatment initially without first needing to demonstrate failure with suboptimal treatments <sup>†</sup>	75%

Percentage agreement is the proportion of respondents selecting ‘agree’ or ‘strongly agree’ (other options were ‘disagree’ and ‘strongly disagree’)

axSpA axial spondyloarthritis, CC Consensus Council, CTA ‘Calls to Action’

\*Multiple statements achieving consensus have been merged for brevity in this table; percentages indicate the level of consensus achieved to the individual statements in the Delphi (for individual statements see supplementary materials)

<sup>†</sup>Statements were taken into the CC meeting to inspire CTA per stakeholder group; these statements were chosen as they describe the desired state and changes to axSpA care so form a foundation for generating CTA

patient outcomes (Table S12). Open-ended questions revealed that cost was seen as the single most important factor in determining which treatment patients with axSpA received. Table 9 contains the overarching CTA and associated stakeholder-specific discussions for the theme of optimal initial treatment. See

Tables S13–S15 in the supplementary materials for the CTA per stakeholder.

## DISCUSSION

The Rheumacensus programme has revealed the current challenges in the management of axSpA

**Table 9** Overarching CTA and associated stakeholder-specific discussions for the theme of optimal initial treatment

No.	Overarching CTA	Stakeholder-specific discussions underpinning each overarching CTA
4.1	Involve the patient perspective in formulary committees and guideline development	<p>To ensure initial treatment in patients with axSpA is optimised, patient representatives and HCPs recognised the importance of patient representation in the development of clinical guidelines</p> <p>Both payors and patient representatives acknowledged their collaborative role in supporting patient knowledge around the treatment options available in axSpA, to facilitate the informed contribution by patients with axSpA at committees and local advisory meetings</p>
4.2	Raise pharmacist awareness of the effects of non-consensual switching to a biosimilar	HCPs acknowledged the importance of consent when switching to a biosimilar and advocated for open communication within multidisciplinary meetings around treatment decisions, rationale and the impact of non-consensual biosimilar switches on patients with axSpA
4.3	Ensure equity of timely access to biologics across regions	<p>Equal access to treatment that considers an individual's needs was advocated by patient representatives and HCPs</p> <p>Payors identified their role in utilising evolving technologies to facilitate treatment monitoring and compare with expectations within clinical guidelines to inform further treatment</p> <p>All stakeholders recognised their role in providing access to optimal initial treatment by reducing any delay to biologic therapy</p>

*axSpA* axial spondyloarthritis, *CTA* 'Calls to Action', *HCP* healthcare professional

across Europe, with a focus on patient empowerment from the perspectives of three key stakeholders: patients, HCPs and payors. By reaching consensus on the current SoC, identifying potential improvements, and proposing CTA, Rheumacensus provides a framework to drive key stakeholders to elevate the SoC for patients with axSpA.

The stakeholder leads shared area of focus which informed the modified Delphi process was: *patient empowerment through education on the disease and treatment options available, to enable patient involvement in management and ultimately increase treatment adherence.*

Overall, 62 statements reached consensus throughout the Delphi process, 17 of which were used in the CC meeting to stimulate the development of CTA per stakeholder group.

Despite some initial statements not reaching consensus, useful insights into the current and desired state/action were revealed by comments of those who disagreed, aiding refinement of some statements for revoting. The four key themes identified were interconnected, stemming from the shared area of focus—patient empowerment, patient knowledge, patient–HCP consultations and optimal initial treatment.

Overarching CTA for each theme highlight what is required to bridge the gap between the current and desired state/action in axSpA (Table 10), while individual stakeholder-specific CTA provide stakeholders with implementable actions that could contribute towards achieving the overarching goal (see supplementary materials). Providing CTA specific to

**Table 10** Summary of overarching CTA generated across each of the four themes

Theme	No.	CTA
Patient empowerment	1.1	Make patients aware of their role and rights in their care and support them to voice their experience, ask questions and state their treatment goals
	1.2	Audit currently available patient empowerment measures and tailor these to individual patient needs before implementation in the clinic
Patient knowledge	2.1	Provide patients with bite-sized, interactive, educational resources, tailored to their individual needs, on any aspect of living with axSpA that interests them (including clinical, holistic and health economic topics)
	2.2	Forge collaborations between HCPs and patient representatives to co-create, validate, and distribute high-quality information to patients and become the recognised sources of reliable and accessible information
Patient–HCP consultations	3.1	Support patients to confidently converse with HCPs
	3.2	Actively listen to the patient’s lived experience of axSpA and take this into account rather than solely using laboratory results/clinical findings to guide management
	3.3	Collaborate with specialist rheumatology nurses to ascertain patients’ individual needs to inform and set tailored treatment goals
	3.4	Structure and tailor consultations according to the patient’s agenda to cover all aspects of axSpA management important to each individual patient and reach a shared treatment decision
Optimal initial treatment	4.1	Involve the patient perspective in formulary committees and guideline development
	4.2	Raise pharmacist awareness of the effects of non-consensual switching to a biosimilar
	4.3	Ensure equity of timely access to biologics across regions

Overarching CTA that all stakeholders could contribute to addressing were developed post CC meeting on the basis of the collation of stakeholder-specific CTA generated within the meeting  
*axSpA* axial spondyloarthritis, *CC* Consensus Council, *CTA* ‘Calls to Action’, *HCP* healthcare professional

each stakeholder at an achievable level gives a responsibility to each person involved in axSpA care and demonstrates the need for individual actions and multidisciplinary collaboration to realise the overarching CTA. Aspects related to patient empowerment underpin most CTA and so activities implemented to address one CTA may synergistically influence another within and/or across the four themes.

The CTA developed ranged from patient rights, effective communication, collaboration and education between stakeholders, personalised care and treatment access—highlighting the complexity of a multidisciplinary approach in axSpA management. It is evident that patient

empowerment is only partly established through educating patients with axSpA on their disease—the HCP has a critical role in creating an environment that encourages empowerment. Whilst a person with axSpA can ask questions and raise concerns, the HCP needs to be receptive and supportive of their involvement. Therefore, HCP education on SDM and collaborative working is needed to help frame conversations with the patient, validating the patient’s role as a key stakeholder within axSpA care. A lack of time in appointments was recognised as a key barrier to HCPs fostering empowerment of patients and involvement in treatment decisions, but it is also important to

note that patient empowerment is not remunerated in most healthcare systems so lacks incentive [16]. The Rheumacensus CC are taking forwards the CTA in their own peer groups and organisations to challenge these barriers and drive the movement for change towards patient empowerment.

Overarching CTA differ by how readily actionable they are. For example, future initiatives based on CTA 1.1, 3.1 and 4.2 (Table 10) may require modest funding, be straightforward to implement and could be realised within a relatively short timeframe. However, initiatives based on CTA 4.1 and 4.3 (Table 10) could necessitate substantial shifts in healthcare systems and practices, requiring more funding and time to address.

Unmet needs recognised within the Rheumacensus programme spanned across patient empowerment, multistakeholder education, access to high-quality materials, SDM and appropriate and timely treatment access. The CREA project (Spain) aimed to understand limitations in the current SoC in patients with axSpA and identify improvement strategies [17]. The CREA project revealed the most prominent limitations to care were lack of resources and time for clinical visits, as well as delays in diagnostic imaging [17], overlapping the Rheumacensus findings around the lack of time that HCPs have for consultations. In contrast to the Rheumacensus programme which involved multiple stakeholders from across Europe, the CREA project solely explored the perspective of Spanish rheumatologists, with 94% having worked in a public health hospital [17]. Other modified Delphi approaches undertaken to reach consensus within axSpA and wider rheumatology care (e.g. to reach consensus on a definition of axSpA remission [18] or provide consensus recommendations to enhance biologic prescribing in the UK for immune-mediated inflammatory diseases [19]) often lack pan-European and/or patient representation.

The Assessment of SpondyloArthritis international Society (ASAS) task force has previously followed a similar method to Rheumacensus to develop a set of nine quality standards to help improve the quality of healthcare for patients with axSpA worldwide.

The ASAS taskforce, comprising 20 rheumatologists, two physiotherapists and two patients, proposed 34 key areas of quality improvement to ASAS members and patients, which were grouped by category, voted on and prioritised. Five key areas were identified as the most important to determine quality of care: referral including rapid access, rheumatology assessment, treatment, education/self-management and comorbidities. Education on the disease, the treatment options available and the role of exercise to facilitate self-management were recognised by both ASAS and Rheumacensus; however, the quality statements have a paternalistic and passive view to education, rather than educating patients so that they can be actively involved in their care and treatment decisions. The quality statements have an overall focus on management of disease activity rather than patients' individual goals, which may be explained by the selection of participants, as many more HCPs than patients were involved throughout the ASAS process. The equal recruitment of stakeholders in Rheumacensus ensured that all perspectives were captured equally, which revealed the shared area of focus of patient empowerment. Rheumacensus further adds to the quality standards by providing a payor viewpoint in addition to HCP and patient perspectives for a holistic view of the challenges faced by each pivotal stakeholder involved in axSpA care. The CTA in Rheumacensus also propose realistic and tangible changes to care for all stakeholders to action, whereas the ASAS task force propose aspirational statements without providing the onus or specific actions to any particular group [20].

Personalised care was intertwined throughout the Rheumacensus programme, with consensus statements and further insights acknowledging the need to consider holistic treatment based on patient phenotype, gender, and socio-economic factors within axSpA care. Similarly, research by Marzo-Ortega et al. [10] revealed gender disparities that exist in terms of representation in clinical research, time to diagnosis, treatment outcomes and HR-QoL. Contributing factors included poor awareness of gender differences in disease manifestation, reported pain, historical biases that axSpA is a

male disease and social factors (e.g. employment, marital status) [8, 10, 21]. Consequently, women experience frequent misdiagnosis and diagnostic delay compared with men, leading to detrimental impacts on HR-QoL and psychological health [10]. Raising awareness of gender disparities through HCP training, further research into gender-adjusted measurement tools and gender-stratified clinical trials are required [10]. These findings are consistent with Rheumacensus. However, the Rheumacensus programme aims to make the next step via the development of CTA to help realise these needs e.g. CTA 1.2 and 3.2 can help address these gender disparities (Table 10).

The strengths and uniqueness of the Rheumacensus programme are the inclusion of three key stakeholder groups involved in the front-line management of axSpA and representation from more than nine countries across Europe to gain a truly pan-European, broad perspective, setting this programme apart from others in axSpA. Limitations include the subjective grouping of the consensus statements and CTA and that not all statements were taken to the CC meeting, leaving some statements and potential CTA unaddressed. However, whilst the selection of statements was subjective, it was based on statements that described the desired state/action and so lent themselves to inspire CTA and those that were omitted often informed implementation and will therefore be considered when creating initiatives to address the CTA. A further limitation was that some stakeholders were unable to attend the virtual CC meeting and so there was incomplete representation of patient representatives and HCPs in live discussions (Fig. 1, Table 1). To partially mitigate this, absent stakeholders provided their CTA in writing post-meeting. Rheumacensus aimed to recruit a diverse stakeholder panel, but one-third of CC members were female (Fig. 1, Table 1). The small size of the stakeholder group is also a limitation, as well as the same group of stakeholders completing the Delphi e-consultations and participating in the development of the CTA; these factors may limit generalisability of the CTA and restrict the range of perspectives. However, the 12 stakeholders represented nine

European countries, bringing a broad geographical perspective to the programme to ensure widely implementable CTA across Europe. The inclusion of an industry sponsor may represent a limitation of this programme. However, Delphi e-consultations were completed by stakeholders independently and the sponsor did not take an active part in the CC meeting.

## CONCLUSION

The Rheumacensus programme has identified key unmet needs in the current SoC in axSpA, with a focus on patient empowerment and proposed CTA to bridge the disparities observed in axSpA care—setting the foundation for change. However, it is now imperative for all stakeholders to take practical steps towards addressing these CTA across Europe to improve the level of patient empowerment through education, effective communication, SDM, personalised care and increased awareness and timely access of appropriate treatment choices, to elevate the SoC for patients with axSpA.

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virtually during the meeting or via email post-meeting. All authors were fully responsible for all content and editorial decisions, were involved at all stages of manuscript development and have approved the final version.

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**Data Availability.** All data generated or analysed during this study are included in this published article/as supplementary information files.

### Declarations

**Conflict of Interest.** Stakeholder leads (namely, Andri Phoka, Bart J.F. van den Bemt and Xenofon Baraliakos) received an honorarium for their participation in the initial workshop and they and the other axSpA CC members (Ennio Lubrano, Inderjit Singh, Cristina Fernández-Carballido, Detlev Parow, Dale Webb, Fabienne Lacombe) received an honorarium from UCB for their time to complete the Delphi e-consultations and to attend the axSpA CC meeting or provide their input offline. UCB Pharma reviewed the manuscript to ensure scientific and medical clarity and accuracy only. Bart J.F. van den Bemt received honorarium for lectures/presentations from Lilly and support for attending meetings from AbbVie, Lilly and UCB. Cristina Fernández-Carballido received honoraria for lectures/presentations from AbbVie, Galapagos, Lilly, Novartis, Pfizer and UCB; consulting fees from AbbVie, Lilly, Novartis and UCB and support for attending meetings from AbbVie, Galapagos, Janssen, Lilly, Novartis, Roche and UCB. Detlev Parow received honoraria for advisory boards from Boehringer-Ingelheim, Hexal and UCB. Ennio Lubrano received honoraria for advisory boards and conference fees from AbbVie, Lilly, Novartis and UCB. Laura Harrington is an employee of Ogilvy Health. Xenefon Baraliakos received consultancy, research funding and honoraria from

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**Ethical Approval.** There was no need to collect any type of patient data. Hence, the approval of an ethics committee was not required. Consent was obtained from all axSpA CC members as they were contracted by UCB Pharma to take part in this programme.

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