Supplementary material

Elevating the standard of care for patients with psoriatic arthritis: 'Calls to Action' from a multistakeholder pan-European initiative

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Table S1. Members of the PsA Rheumacensus CC

CC members	Background	Country
Patient representatives		
Iris Verbinnen (group lead)	Post-doctoral researcher, Laboratory of Protein Phosphorylation and Proteomics, Department of Cellular and Molecular Medicine, University of Leuven; Leuven Brain Institute, Leuven	Belgium
Antonella Celano* Replaced by: Andrea Tomasini	President of APMARR, Lecce APMARR, Lecce	Italy
Fabienne Lacombe	Director of AFS	France
Edita Müllerová	President of The Czech League Against Rheumatism	Czech Republic
HCPs		
Philip S Helliwell (group lead)	Leeds Institute of Rheumatic and Musculoskeletal Medicine, University of Leeds and Leeds Musculoskeletal Biomedical Research Unit, Leeds Teaching Hospitals NHS Trust	UK
Ulrike Erstling	Chair of the German Rheumatology Nurse's Organisation	Germany
Andreas Pinter	Department of Dermatology, Venereology and Allergology, University Hospital Frankfurt am Main	Germany
Arno WR van Kuijk	Amsterdam Rheumatology and Immunology Center, Reade, Amsterdam	The Netherlands
Payors		
Emilio Monte-Boquet (group lead)	Pharmacist, La Fe University Hosptial, Valencia	Spain
Detlev Parow	Formerly Department of Medicines, Therapeutic Appliances and Remedies, DAK-Gesundheit, Hamburg	Germany
Andrew Pothecary	Lead Pharmacist, Rheumatology & Biologics at Royal Cornwall Hospitals NHS Trust	UK
Hedye van Ameijden	Managing Pharmacist, Reade, Amsterdam	The Netherlands

*Antonella Celano completed all three Delphi e-consultations and then was replaced by Andrea Tomasini for the CC meeting.

AFS, The France Spondyloarthritis Association; APMARR, Italian National Association of People with Rheumatological and Rare Diseases; CC, Consensus Council; HCP, healthcare professional; NHS, National Health Service.

Methods

Table S2. Unmet needs, challenges and barriers identified within the stakeholder leads workshop per stakeholder group

Patient representative	Disconnected patient-physician goals
	Understanding treatment options
	Timely referral for diagnosis
	Appropriate mental health care
	A system to quickly get help with worsening symptoms
	Lack of patient empowerment – need accessible information and connection to patient associations
Payor	Treatment access differs across regions
	Real and effective integration of the pharmacist into the MDT, and a clear definition of the pharmacist's role
	Care plans encompassing individual patient needs to tailor pharmaceutical care
	Adherence (need to find the causes of poor adherence)
	Telepharmacy (need to find which patients benefit from it and which prefer face-to-face)
	Lack of real-world data evaluating treatment results
	Patient-reported outcomes are not currently considered in treatment decisions
	We should optimise delivery and communication of care to make patient lives easier
	Poor resource coupled with high workloads
	Limited knowledge of PsA and the complexity of management in the general pharmacist community (excluding specialists)
HCPs	Timely referral to rheumatologists
	Timely diagnosis and initiation of treatment after referral
	Setting goals and agreeing targets with patients
	Lack of MDT working
	Assessment is suboptimal – need regular and appropriate (e.g., face-to-face) assessment
	There are no systems in place for patients to use if they experience a flare or problem with treatment

HCP, healthcare professional; MDT, multidisciplinary team; PsA, psoriatic arthritis.

Results

Table S3. All statements included in the Delphi process pertaining to patient empowerment (Theme 1)

Statement	Percentage agreement
Patient empowerment is the process by which people are supported to gain sufficient knowledge, to enable them to be as actively involved as they want to be in making decisions that shape their health	83%
The level of patient empowerment of patients with PsA is low to moderate	83%
There is room for improvement in the level of patient empowerment in PsA	100%

Patients with PsA and a poor socio-economic background have lower levels of empowerment than those with higher socio-economic backgrounds	83%
Patients with PsA and a low education level are less empowered than those with higher education levels	100%
To improve patient empowerment, there is a need to improve knowledge of the disease and treatment options in patients with PsA*	100%
Empowering patients with PsA to be involved in their own care will improve their outcomes	100%
Patient empowerment will drive patients with PsA to aspire to treatment targets that are higher than those they previously aspired to	75%
Patient empowerment has a role in patients demanding higher treatment targets than they previously aspired to in PsA	75%
Patients should be empowered to seek complete resolution of all symptoms of PsA to improve their QoL	75%
The level of empowerment of patients with PsA affects treatment decisions	92%
The level of empowerment of patients with PsA influences how HCPs communicate with them	100%
Self-monitoring of symptoms by patients with PsA improves their consultations with HCPs	100%
There is a need for reliable ways of measuring patient empowerment in PsA	92%
The pharmaceutical industry has a key role to play in supporting the empowerment of patients with PsA	75%
One way that pharmaceutical companies could support the empowerment of patients with PsA is by supporting patient organisations to create resources and deliver initiatives and educational programmes	83%
Patient organisations have a key role to play in supporting the empowerment of patients with PsA	100%
Patient advocacy groups play a greater role in supporting less empowered patients with PsA than more empowered patients	83%
Patient organisations should provide high-quality educational materials to HCPs	58%
Patient organisations should provide high-quality educational materials to payors	83%
HCPs have a key role to play in supporting the empowerment of patients with PsA	100%
Lack of time is the largest barrier preventing HCPs from supporting patient empowerment in PsA	92%
Payors have a key role to play in supporting the empowerment of patients with PsA	83%
Improved communication between payors, patients and HCPs will lead to greater empowerment of patients with PsA	92%

Bold statements were taken into the CC meeting to inspire CTA. Italics indicate statements that did not reach consensus. Shaded rows indicate statements that were not taken to the CC meeting but still helped shape the narrative.

*Statement used in both the patient empowerment and patient knowledge and sources of education narratives.

CC, Consensus Council; CTA, 'Calls to Action'; HCP, healthcare professional; PsA, psoriatic arthritis; QoL, quality of life.

Table S4. Overarching CTA for the theme of patient empowerment and the underpinning stakeholder-specific CTA

Overarching CTA
Ensure all patients receive the support they need to be empowered
CTA for each stakeholder

Patient representatives must: • Support the development of a tool to measure patient empowerment • Provide materials to support patient education developed with patient input	**HCPs must:** • Guide patients to appropriately funded and skilled personnel for education on the disease and processes of care	**Payors must:** • Raise awareness of what is available for patients in terms of treatments • Encourage integration of hospital pharmacists into the MDT, ensuring their functions are clearly defined so that the patient recognises them as another member of the professional team

CTA, 'Call(s) to Action'; HCP, healthcare professional; MDT, multidisciplinary team.

Table S5. Overarching CTA for the theme of patient empowerment and the underpinning stakeholder-specific CTA

Overarching CTA		
Improve the visibility of patients and patient organisations to bolster patient support and strengthen the patient voice at an organisational level		
CTA for each stakeholder		
Patient representatives must: • Raise awareness of the role of patient representatives and services they can provide (to HCPs and patients) so that all patients know their local patient organisations and how to contact them	**HCPs must:** • Inform patients about other contact points who can help support and provide them with information	**Payors must:** • Financially support patient organisations • Facilitate the inclusion of patients on committees and advisory boards • Improve communication with governments about the benefit of patient empowerment

CTA, 'Call(s) to Action'; HCP, healthcare professional.

Table S6. Overarching CTA for the theme of patient empowerment and the underpinning stakeholder-specific CTA

Overarching CTA		
Support patients to understand life with a chronic condition and HCPs to communicate effectively with patients so they appreciate the patient's lived experience		
CTA for each stakeholder		
Patient representatives must: • Capture the lived experience of empowerment for all patients with PsA • Bridge the gap between the lived experience of the patient and the HCP's clinical perspective and how care is delivered in society • Help to train patients with PsA to listen to their body, understand what it is to live with a chronic condition, make informed decisions relevant to their own disease status and aspire to high treatment targets • Support HCPs to communicate effectively with patients	**HCPs must:** • Establish a trustful relationship with the patient to be able to gather other important information and personal aspects of the disease • Educate and communicate with patients in a time-efficient way	**Payors must:** NA

When NA is stated no stakeholder-specific CTA were developed during the CC meeting.
CC, Consensus Council; CTA, 'Call(s) to Action'; HCP, healthcare professional, MDT, multidisciplinary team; NA, not applicable; PsA, psoriatic arthritis.

Table S7. All statements included in the Delphi process pertaining to patient knowledge and sources of education (Theme 2)

Statement	Percentage agreement
A patient with PsA must be sufficiently knowledgeable about their disease to be included in making treatment decisions	92%
A patient with PsA must be sufficiently knowledgeable about the available interventions to be included in making treatment decisions	100%
Patients with PsA are already sufficiently knowledgeable about their disease	8%
Revised statement based on comments: Patients with PsA should be given the opportunity and educational materials to learn about their disease and treatment options	100%
There is room for improvement in the level of patient knowledge about PsA and the treatment options available	100%
To improve patient empowerment, there is a need to improve knowledge of the disease and treatment options in patients with PsA*	100%
Education of PsA should be tailored to the patient's capacity to learn and understand	92%
Education about disease-measuring tools will lead to greater use of these tools in clinical practice	92%
Patients with PsA need easily accessible, high-quality, neutral information about their disease	100%
One of the major barriers to patients accessing high-quality information is the large amount of low-quality information that is readily available	75%
The internet is the main source of low-quality educational resources about PsA for patients	67%
Revised statement based on comments: The internet is a source of both high- and low-quality education about PsA and the available treatment options	92%
Patients with PsA need support to identify high-quality education on their disease and the available treatment options	100%
Patients need more high-quality information on how to manage all aspects of PsA (e.g. relationships, mental health, adverse events, employment etc.)	100%
Patients with PsA should be educated on the role of patient organisations and how to contact them	100%
HCPs are key to providing high-quality education for patients with PsA	92%
HCPs should be responsible for providing patients with clear direction to high-quality education about their disease	100%
HCPs do not always have sufficient time to provide all the high-quality education that patients with PsA need	92%
Patients with PsA should be directed to patient organisations as sources of high-quality education	92%
Patient organisations should be responsible for providing patients with clear direction to high-quality education about their disease	83%
HCPs are most open to shared decision-making when patients with PsA show a high level of understanding of their disease and the treatment options available	100%

Bold statements were taken into the CC meeting to inspire CTA. Italics indicate statements that did not reach consensus. Shaded rows indicate statements that were not taken to the CC meeting but still helped shape the narrative.

*Statement used in both the patient empowerment and patient knowledge and sources of education narratives.

CC, Consensus Council; CTA, 'Calls to Action'; HCP, healthcare professional; PsA, psoriatic arthritis.

Table S8: Overarching CTA for the theme of patient knowledge and sources of education and the underpinning stakeholder-specific CTA

Overarching CTA		
Collaborate to develop tailored, holistic educational materials, with patient input, covering the full patient journey from diagnosis with a chronic disease through all life stages		
CTA for each stakeholder		
Patient representatives must: • With input from HCPs, provide easily accessible educational materials for patients • Collaborate with HCPs and patient organisations to deliver educational sessions for patients • Explore the scientific literature and conferences to listen, understand and translate anything that would have an impact on the daily life of patients with PsA	**HCPs must:** • Educate patients on the systemic nature of PsA and associated comorbidities • Involve the MDT in educating patients on all aspects of disease • Check with the patient on their understanding of the information provided • Share practical experiences with pharmaceutical companies to inform the production of brochures on different topics	**Payors must:** • Service specifications to include specific topics of disease and treatment tailored to level of education and on a cultural level, further to purely translation

CTA, 'Call(s) to Action'; HCP, healthcare professional; MDT, multidisciplinary team; PsA, psoriatic arthritis.

Table S9: Overarching CTA for the theme of patient knowledge and sources of education and the underpinning stakeholder-specific CTA

Overarching CTA		
Direct patients to high-quality, validated, easy-to-access educational material		
CTA for each stakeholder		
Patient representatives must: • Ensure all patients are aware of where they can access high-quality information	**HCPs must:** • Identify and signpost patients to good quality information on all aspects of disease • Continue to support and direct patients to reliable sources of information despite patients favouring low-quality sources of education • Validate sources of information before referring patients to that information	**Payors must:** • Support accreditation of the development process and creation of a quality stamp for sources • Direct patients to patient organisation websites as a source of reliable information about their disease

CTA, 'Call(s) to Action'; HCP, healthcare professional.

Table S10: Overarching CTA for the theme of patient knowledge and sources of education and the underpinning stakeholder-specific CTA

Overarching CTA		
Educate more broadly, beyond the patient, to improve knowledge of PsA among dermatologists and the public		
CTA for each stakeholder		
Patient representatives must: NA	**HCPs must:** • Educate dermatologists to inform their patients with psoriasis about the potential for joint involvement and the need for a rheumatologist	**Payors must:** • Educate general public, not just patients

When NA is stated no stakeholder-specific CTA were developed during the CC meeting.
CC, Consensus Council; CTA, 'Call(s) to Action'; HCP, healthcare professional; NA, not applicable; PsA, psoriatic arthritis.

Table S11: All statements included in the Delphi process pertaining to patient–HCP consultations (Theme 3)

Statement	**Percentage agreement**
HCPs must treat the whole patient and not just treat their PsA	100%
HCPs recognise the full burden of PsA on patients	66%
HCPs should ask questions to establish the full burden of PsA on all aspects of the patient's life, rather than relying on the patient to proactively volunteer information	100%
HCPs need to be educated by patient organisations on the full burden of PsA	75%
HCPs need support to enable them to communicate effectively with patients around the full burden of their PsA	100%
Treatment choice should be based on the individual needs of each patient with PsA*	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	100%
HCPs should consider gender-specific factors when making treatment decisions with patients with PsA	92%
Patients with PsA are always routinely involved in treatment decisions	17%
Revised statement based on comments: Many patients are not aware that they have an option to be involved in treatment decisions	92%
Patients should be educated on what they are entitled to in terms of their level of involvement in treatment decisions	100%
HCPs should ask to what extent each patient would like to be involved in their treatment decisions	100%
Patients with PsA and HCPs must align on treatment goals before deciding on a treatment	92%
Treatment targets should be described 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%
Complete resolution of all symptoms of PsA is an achievable goal	75%
Patients with PsA and their HCPs should have an equal say when deciding which interventions to use	83%
In the event that a patient with PsA and their HCP disagree on a treatment decision, the HCP should have the final say	25%
In the event that a patient with PsA and their HCP disagree on a treatment decision, the patient should have the final say	58%

Revised statement based on comments: **In the event that a patient with PsA and their HCP disagree on a treatment decision, efforts should be made to reach a shared decision through further discussion**	100%
Patients with PsA should be regularly assessed for satisfaction with their treatment regardless of clinical assessments of treatment response	92%
One of the major barriers preventing HCPs from including patients in treatment decisions is the time required to explain the disease and treatment options available	100%
One of the main reasons preventing patients being involved in treatment decisions is that HCPs do not ask them to be involved	83%

Bold statements were taken into the CC meeting to inspire CTA. Italics indicate statements that did not reach consensus. Shaded rows indicate statements that were not taken to the CC meeting but still helped shape the narrative.

*Statement used in both the patient–HCP consultations and the initial optimal treatment narratives.

CC, Consensus Council; CTA, 'Calls to Action'; HCP, healthcare professional; PsA, psoriatic arthritis.

Table S12. Overarching CTA for the theme of patient–HCP consultations and the underpinning stakeholder-specific CTA

Overarching CTA		
Support HCP communication techniques, including active listening, motivational interviewing and soft skills		
CTA for each stakeholder		
Patient representatives must: • Help doctors learn how to communicate more effectively with patients – teach them to listen (not just hear) so they fully understand the complete disease burden from the patient's perspective • Support HCPs to communicate effectively with patients (soft skills, the language they use, etc.)	**HCPs must:** • Improve active listening • Ask patients about their treatment goals in the general consultation • Establish a trustful relationship with the patient to be able to gather other important information and personal aspects of the disease	**Payors must:** • Incorporate the motivational interview in the medical and pharmaceutical consultation and adequately train the HCP to carry it out

CTA, 'Call(s) to Action'; HCP, healthcare professional.

Table S13. Overarching CTA for the theme of patient–HCP consultations and the underpinning stakeholder-specific CTA

Overarching CTA		
Optimise patient involvement in SDM		
CTA for each stakeholder		
Patient representatives must: • Raise awareness among patients that they can be involved in treatment decisions and encourage HCPs to be open to patient involvement • Train patients so they are equipped to understand their experience and what they can expect from treatment (to get the best life possible) so they can share their thoughts and treatment goals with their HCP	**HCPs must:** • Ensure the patient agrees on all aspects when initiating pharmacological treatment • Support patients to be well informed about their condition and to ask questions about it in order to learn to cope with their new life situation • Explain to patients the advantages and, if applicable, disadvantages of each treatment option	**Payors must:** • Accept patient as 'co-producer' of their health; patient involvement/SDM should be implemented into medical training • Teach patients how to prepare for a medical or pharmaceutical consultation so as not to forget to convey or ask relevant questions to the HCP • Encourage HCPs to share with the patient all the relevant information regarding their illness and treatment, giving them the opportunity to express their opinion and participate in the decisions

CTA, 'Call(s) to Action'; HCP, healthcare professional; SDM, shared decision-making.

Table S14. Overarching CTA for the theme of patient–HCP consultations and the underpinning stakeholder-specific CTA

Overarching CTA		
Develop and utilise new and existing tools to better prepare patients for consultations		
CTA for each stakeholder		
Patient representatives must: • Facilitate patient–HCP conversations by providing questionnaires to structure conversations	**HCPs must:** • Set small achievable goals and then rethink the next steps at each stage to implement them in mutual agreement	**Payors must:** • Identify the use of decision aids for patients post-consultation (web-enabled patient decision aid tailored towards level of education) • Establish how well patients feel they have been listened to (survey post-consultation)

CTA, 'Call(s) to Action'; HCP, healthcare professional.

Table S15. All statements included in the Delphi process pertaining to optimal initial treatment (Theme 4)

Statement	Percentage agreement
Payors prioritise cost considerations of PsA treatments across the population over individual patient outcomes	75%
Prioritising cost considerations over optimal initial treatment for patients with PsA negatively affects treatment decisions	75%
Prioritising cost considerations over optimal initial treatment for patients with PsA can lead to poor patient outcomes	83%
Payors should be educated on the burden of PsA	92%
Payors need to be educated by patient organisations on the full burden of PsA	100%
Treatment choice should be based on the individual needs of each patient with PsA*	100%
Optimal initial treatment on a patient-by-patient basis will result in wider and earlier use of biologics in PsA	83%
Payors should be educated on how to communicate with relevant stakeholders (e.g., HCPs, patients, societies, etc.)	83%
There should be closer links between payors, national HCP organisations and patient organisations, so that payors can gain a better understanding of the unmet needs of patients with PsA	100%

Bold statements were taken into the CC meeting to inspire CTA. Shaded rows indicate statements that were not taken to the CC meeting but still helped shape the narrative.
*Statement used in both the patient–HCP consultations and the initial optimal treatment narratives.
CC, Consensus Council; CTA, 'Calls to Action'; HCP, healthcare professional; PsA, psoriatic arthritis.

Table S16. Overarching CTA for the theme of optimal initial treatment and the underpinning stakeholder-specific CTA

Overarching CTA		
Improve collaboration and engagement of payors with patients and patient organisations, to augment a reciprocal understanding of each other's role and perspectives		
CTA for each stakeholder		
Patient representatives must: • Engage with payors (and their superiors), start a dialogue: educate them on the full burden of PsA by sharing the lived experience of patients so they understand patient needs • Help payors to understand treatment sustainability from the patient perspective (not just the economic perspective): how sustainable treatments are in the context of a patient's lifestyle, stage of disease, disease progression, employment, the burden of taking the therapy, etc.	**HCPs must:** • Support patient organisations to inform the payors on the full burden of PsA and be heard in health policy discussions	**Payors must:** • Communicate the defined role of the payor to the patient (according to guidelines) and increase awareness of the pharmacist as a partner to the HCP • Maintain positive communications with patients about treatment decisions

CTA, 'Call(s) to Action'; HCP, healthcare professional; PsA, psoriatic arthritis.

Table S17. Overarching CTA for the theme of optimal initial treatment and the underpinning stakeholder-specific CTA

Overarching CTA		
Personalise treatment by utilising assessment tools to monitor patient treatment journey and response		
CTA for each stakeholder		
Patient representatives must: • Help to prepare patients for their treatment: if they are aware of the options available (including for all life stages), understand what they can expect to gain from the treatment, what to expect when starting or switching treatment, how to communicate their own individual needs and ideal treatment choice to HCPs	**HCPs must:** • Ensure treatment targets are personalised to all aspects important to the patient • Encourage payors to incentivise a treat-to-target approach	**Payors must:** • Systematically assess the response to treatments, both individually to see if a change is needed • Have a multidisciplinary committee in which shared and transparent decisions are made on the initial treatment of each patient, depending on their particular situation, and on the necessary changes throughout the treatment

CTA, ‘Call(s) to Action’; HCP, healthcare professional.

Table S18. Overarching CTA for the theme of optimal initial treatment and the underpinning stakeholder-specific CTA

Overarching CTA		
Adopt data, tools and algorithms to better understand drug comparisons and optimal treatment		
CTA for each stakeholder		
Patient representatives must: NA	**HCPs must:** NA	**Payors must:** • Advocate for more granular homecare data (in terms of disease and indication) and implement digital technologies to analyse this • Systematically assess the response to treatments globally from a pharmacoeconomic point of view to see if a change is needed • Develop algorithms to establish the right drug for the right patient • Use data comparison tools to benchmark against other centres, ensuring the data are not taken at face value

When NA is stated no stakeholder-specific CTA were developed during the CC meeting.
CC, Consensus Council; CTA, ‘Call(s) to Action’; HCP, healthcare professional; NA, not applicable.