Supplementary Material

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

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Insights-gathering questionnaire

The questions completed by each stakeholder are indicated by the stakeholder icons next to the question number:

 Clinician  Payor  Patient representative

Question 1. 

Q1a. When you think of the term 'burden of disease' and how this relates to psoriasis, what do you, in your role, consider to be the top three factors that define the burden?

-
-
-

Q1b. How do you consider the burden of psoriasis, as you have defined it, has changed over the last 5 years? **Please select one option**.

Increased significantly ☐

Increased ☐

No change ☐

Improved ☐

Significantly improved ☐

Q1c. How do you see the burden, as you have defined it, changing over the *next* 3 years? **Please select one option**.

Increasing significantly ☐

Increasing ☐

No change ☐

Improving ☐

Significantly improving ☐

Question 2 

Q2a. Over the **last 3 years**, from your perspective, what three factors do you think have been the most significant in helping elevate the standard of care for patients with psoriasis?

-
-
-

Q2b. How do you consider the standard of care for patients with psoriasis has changed over the ***last* 3 years**?

Elevated significantly ☐

Elevated slightly ☐

No change ☐

Decreased slightly ☐

Decreased significantly ☐

Q2c. How do you see the standard of care for patients with psoriasis changing over the ***next* 3 years**?

Elevated significantly ☐

Elevated slightly ☐

No change ☐

Decreased slightly ☐

Decreased significantly ☐

Question 3 

Q3a. When you think of the term 'increased value' (e.g. clinical, health economic, societal, patient and carer perspective, organisational) as it relates to elevating the standard of care for patients with psoriasis, what are your top five considerations? **Please prioritise your answers (1–5)**

1.
2.
3.
4.
5.

Q3b. Do you consider the term *'increased value'* as it relates to *elevating the standard of care* for patients with psoriasis:

Very easy to define ☐

Easy to define ☐

Unsure how to define ☐

Difficult to define ☐

Very difficult to define ☐

Question 4 

Q4a. What are the most important gaps in the existing *care pathway* for patients with psoriasis? **Please prioritise your answers (1–3)**

1.
2.
3.

Q4b. How much do these gaps in the care pathway impact on being able to *elevate the standard of care* for patients with psoriasis?

Very impactful ☐

Some impact ☐

Unsure ☐

No real impact ☐

Q4c. On a scale of 1–5, how equitable is access to optimal care for patients with psoriasis in your country? Please select one option

1. Fully equitable across the country ☐
2. ☐
3. ☐
4. ☐
5. Significant inequality in terms of access ☐

Unsure ☐

Question 5

Q5a. What *current barriers* do you see to maximising outcomes and *elevating the standard of care* for patients with psoriasis (e.g. clinical, health economic, patient and carer perspectives, societal, organisational)? **Please prioritise your answers (1–5)**

1.
2.
3.
4.
5.

Q5b. How do you see these barriers changing over the *next* 3 years? **Please select one option**

Easy to overcome these barriers ☐

Some success in overcoming these barriers ☐

Unsure of any change taking place ☐

Sure there will be no change to existing barriers ☐

Sure the barriers will increase ☐

Q5c. What role do you consider the biopharmaceutical industry plays in helping overcome your NUMBER 1 barrier? **Please select one option**

Very significant role ☐

Significant role ☐

Some role ☐

Unsure of any role ☐

No role ☐

Question 6 

Q6a. What specific outcomes or indicators of treatment success (e.g. clinical, health economic, patient and carer perspective, societal, organisational) are the most *valuable for you* in terms of your assessment of an effective therapeutic intervention in the management of psoriasis?
Please prioritise your answers (1–5)

1.
2.
3.
4.
5.

Q6b. Generally, how well are these outcomes captured within clinical trials, real-world evidence and medical practice? **Please select one option**

Outcomes captured comprehensively ☐

Outcomes captured, but variable ☐

Unsure ☐

Outcomes not captured ☐

The wrong outcomes captured ☐

Q6c. What role do you consider the biopharmaceutical industry plays in driving improvement in health outcomes for patients with psoriasis? **Please select one option**

Very significant role ☐

Significant role ☐

Some role ☐

Unsure of any role ☐

No role ☐

Question 7

Q7a. What are the top five changes you would like to make (e.g. clinical, health economic, patient and carer perspective, societal, organisational) to enhance the existing approach to the management of psoriasis and elevate the standard of care? **Please prioritise your answers (1–5)**

1.
2.
3.
4.
5.

Q7b. How challenging do you feel your NUMBER 1 priority change will be to achieve in the next 12 months? **Please select one option**

Very easy to achieve ☐

Some potential to achieve ☐

Unsure any change can be achieved ☐

Sure that no change will be achieved ☐

The change needed will get more challenging ☐

Q7c. What role do you consider the biopharmaceutical industry plays in helping you achieve your NUMBER 1 priority? **Please select one option**

Very significant role ☐

Significant role ☐

Some role ☐

Unsure of any role ☐

No role ☐

Question 8

Q8a. What are the top three changes you would like to make in TREATMENT to enhance the existing approach to the management of psoriasis and help elevate the standard of care? **Please prioritise your answers (1–3)**

1.
2.
3.

Q8b. What role do you consider the biopharmaceutical industry plays in helping you achieve your NUMBER 1 change?

Very significant role ☐

Significant role ☐

Some role ☐

Unsure of any role ☐

No role ☐

Q8c. What are the top three changes you would like to make to TREATMENT GUIDELINES/FORMULARIES to enhance the existing approach to the management of psoriasis and help elevate the standard of care? **Please prioritise your answers (1–3)**

1.
2.
3.

Q8d. What role do you consider the biopharmaceutical industry plays in helping you achieve your NUMBER 1 change?

Very significant role ☐

Significant role ☐

Some role ☐

Unsure of any role ☐

No role ☐

Q8e. What are the top three changes you would like to make to include PATIENTS IN DECISION MAKING to enhance the existing approach to the management of psoriasis and help elevate the standard of care? **Please prioritise your answers (1–3)**

1.
2.
3.

Q8f. What role do you consider the biopharmaceutical industry plays in helping you achieve your NUMBER 1 change?

Very significant role ☐

Significant role ☐

Some role ☐

Unsure of any role ☐

No role ☐

Q8g. What are the top three changes you would like to make ORGANISATIONALLY to enhance the existing approach to the management of psoriasis and help elevate the standard of care? **Please prioritise your answers (1–3)**

1.
2.
3.

Q8h. What role do you consider the biopharmaceutical industry plays in helping you achieve your NUMBER 1 change?

Very significant role ☐

Significant role ☐

Some role ☐

Unsure of any role ☐

No role ☐

Question 9 

Q9a. How do you suggest clinical, payor and patient organisations could Uto elevate the standard of care for patients with psoriasis across all touchpoints with healthcare services and throughout the course of their disease? **Please try to give at least two sentences.**

Q9b. How challenging do you feel this would be to achieve in your country?

Very easy to achieve ☐

Some potential to achieve ☐

Unsure if this would be possible ☐

Sure there is no possibility of this happening ☐

Would like to see this happen but no possibility ☐

Question 10 

Q10a. How would you describe *person-centred healthcare* in the management of patients with psoriasis? What could be enhanced, who should be involved and what could you, in your role, do to optimise existing care for patients? **Please try to give at least two sentences.**

Q10b. How familiar are you with the term *person-centred healthcare*? **Please select one option.**

Very familiar and understand the principle ☐

Some familiarity and understand the principle ☐

Unsure of the term ☐

Never heard of the term ☐

Heard of patient-centred healthcare and assume it is the same ☐

Q10c. What role, if any, do you consider the biopharmaceutical industry plays in helping support person-centred healthcare in psoriasis? **Please select one option.**

Very significant role ☐

Significant role ☐

Some role ☐

Unsure of any role ☐

No role ☐

Question 11

Q11a. How would you describe the impact of the COVID-19 pandemic on the management of patients with psoriasis? **Please try to give at least two sentences**

Q11b. What have we learned about the delivery of care for patients during the COVID-19 pandemic that could lead to improvements in the future delivery of care? **Please try to give at least two sentences**

Q11c. How would you describe the impact of the COVID-19 pandemic on the clinical management of patients with psoriasis? **Please try to give at least two sentences**

Q11d. Have patients observed any positive aspects to the healthcare they have received during the COVID-19 pandemic that could lead to future improvements in the delivery of care? **Please try to give at least two sentences.**

Question 12

Q12a. In the context of increasing pressures on healthcare system resources, what evidence and support do you consider to be effective for facilitating the adoption of new innovative treatments in psoriasis? **Please prioritise your top three answers (1–3)**

1.
2.
3.

Q12b. How do you feel healthcare resources (financial) will change in the management of psoriasis in the next 3 years? **Please select one option**

Substantially increase ☐

Increase slightly ☐

No change ☐

Decrease ☐

Decrease substantially ☐

Q12c. How do you feel healthcare resources (human) will change in the management of psoriasis in the next 3 years? **Please select one option**

Substantially increase ☐

Increase slightly ☐

No change ☐

Decrease ☐

Decrease substantially ☐

Question 13 

Q13a. Where would you like to see more investment of resources made or a redirection of resources to support an elevation in the standard of care for patients with psoriasis? **Please prioritise your answers (1–3)**

1.
2.
3.

Q13b. How likely is this investment to take place in the next 3 years for your NUMBER 1 priority? **Please select one option.**

Very likely ☐

Likely ☐

Unsure ☐

Unlikely ☐

Very unlikely ☐

Q13c. What role do you consider the biopharmaceutical industry plays in helping you achieve your NUMBER 1 priority? **Please select one option.**

Very significant role ☐

Significant role ☐

Some role ☐

Unsure of any role ☐

No role ☐

Question 14 

Q14a. What role does the biopharmaceutical industry play in supporting the elevation in the standard of care for patients with psoriasis? **Please try to give at least two sentences.**

Q14b. What are the top three barriers to effective partnership working between you and the biopharmaceutical industry? **Please prioritise your answers (1–3)**

1.
2.
3.

Q14c. Provide one example (if possible) of an effective partnership project by the biopharmaceutical industry that supported the elevation in the standard of care in psoriasis. **Please try to give at least two sentences.**

Table S1. Members of the Consensus Council

Consensus Council member	Background	Country
Clinicians (dermatologists)		
Matthias Augustin	Academic hospital	Germany
Wolf-Henning Boehncke	Academic hospital	Switzerland
Menno de Rie	Academic hospital	Netherlands
Gabriella Fabbrocini	Academic hospital	Italy
Denis Jullien	Academic Hospital, President of the Psoriasis Group of the French society of dermatology (GRPsO)	France
Jo Lambert	Academic hospital	Belgium
Elizabeth Lazaridou	Academic hospital and private practice	Greece
Lluís Puig	Academic hospital and private practice	Spain
Simon Francis Thomsen	Academic hospital	Denmark
Richard Warren	Academic hospital	UK
Payors		
Loïc Guillevin	Professor of Medicine, former President of the Transparency Commission (HAS)	France
Marcello Pani	Hospital pharmacist	Italy
Anusha Patel	High-cost drugs NHS hospital pharmacist	UK
Patient representatives		
Valeria Corazza	President of Association of Italian Psoriasis Friends of the Corazza Foundation	Italy
Marius Grosser	German Psoriasis Association	Germany
Jan Koren	EUROPSO	Slovenia
Helen McAteer	Psoriasis Association	UK
David Trigos	EUROPSO	Spain

EUROPSO, European Federation of Psoriasis Patient Associations; HAS, Haute Autorité de Santé; NHS, National Health Service.

Materials and Methods

Phase 1: Insights-gathering questionnaire

The insights-gathering questionnaire explored the participants' perspectives on five broad topics relating to elevating the SoC for patients with psoriasis: defining the scope of the challenges in managing psoriasis; possible barriers and solutions to improve the SoC for patients with psoriasis; the role of the patient; the role of the pharmaceutical industry; learnings from the COVID-19 pandemic. To gain a broad, pan-European perspective, the questionnaire (See supplementary information) was completed by 42 participants (21 clinicians [dermatologists], 12 payors and 9 patient representatives) in January 2021.

Phase 2: The modified Delphi process

The expert stakeholder panel

A group of clinicians (n=10), payors (n=3) and patient representatives (n=5) (the Consensus Council) then took part in a modified Delphi process exploring these eight key themes. Members of the Consensus Council (some of whom were involved in Phase 1 while others were new to the programme) are shown in Table S1.

The Delphi e-surveys

Over three rounds of Delphi e-surveys, Consensus Council members were asked to indicate their level of agreement with statements exploring each of the eight themes. The range of possible responses was 'strongly agree', 'agree', 'disagree' or 'strongly disagree'. Consensus was defined as ≥75% selecting 'agree' or 'strongly agree'. Those who did not agree were asked for their reasons to help refine statements with the aim of reaching consensus in subsequent voting. The objective of the meeting was to gain multistakeholder consensus, but the different stakeholders were not equal in number. Therefore, to ensure that each stakeholder group was equally represented, individual votes were weighted so that each stakeholder group had an equal impact on the overall percentage calculated. In addition, some open-ended questions were included in the questionnaires to gain further information.

Phase 3: Consensus council meetings – 'Calls to Action'

After the Delphi exercise, two meetings were held via Zoom on 29th June and 1st July 2021. At these meetings, the Consensus Council members were presented with the consensus statements that provided the greatest potential to inspire practical ideas to bring about change, for each theme in turn. Within their different stakeholder groups, Consensus Council members discussed the statements and were given the task of brainstorming ideas in the form of 'Calls to Action', aligned with the statements, which stakeholders could do to bring about a desirable change that may contribute to an elevation in the SoC. The groups then reconvened to share and discuss their 'Calls to Action'. This publication presents the 'Calls to Action' that were common to all three stakeholder groups.

Calls to action

Table S2. This table presents ‘Calls to Action’, beyond those common to all three stakeholder groups, which were only defined by two stakeholder groups as indicated, per theme.

Theme		‘Calls to Action’		
	Statements	**Clinicians and payors must…**	**Clinicians and patient representatives must…**	**Payors and patient representatives must…**
Improve healthcare systems to better support MDT working and digital services	Digital healthcare encompasses the use of technology in its broadest sense to enhance and improve all aspects of healthcare/management of patients by supporting patients and HCPs through: Facilitating a continuous dialogue between patients and their HCPs; supporting self-assessment and monitoring tools for patients to enable consistent recording of data; storing and sharing data and documentation; facilitating communication between HCPs of different specialities; appropriate use of telemedicine and virtual consultations; and facilitating administration for both HCPs and patients, at all stages of the patient journey		• Convince non-believers of the benefits of digital tools • Increase awareness of digital tools and support general education and training on how to use them, including relevant support for patients • Deploy digital technology to accurately monitor patient outcomes • Help patients to realise the value of embracing technological innovations into daily practice while ensuring data protection	
	Digital healthcare should be made as accessible as possible to all patients with psoriatic disease and/or their caregivers to maximise the number of patients who can benefit from it			

Real-world data generation and optimal use	Real-world data are needed to support the rapid incorporation of novel medicines into clinical guidelines and the refinement of clinical practice		• Ensure that patient data are collected and protected • Facilitate the development of collaborative databases by engagement with other stakeholders (e.g. payors, politicians) • Educate all stakeholders on the value of real-world evidence and help them to realise the importance of PROs in RWD	
	Outcomes that are most important to patients are the most important to measure and collect in routine clinical practice			
	RWD is vital to help inform clinicians of the real-world effectiveness and safety (including long-term data) of different treatments in 'real' patients, i.e. those who are often excluded from clinical trials.			
Improve patient access	Early intervention, with effective biologic treatments, may provide long-term value for patients and healthcare systems		• Support adoption of digital tools to enable remote access to specialists and MDT working	
	Healthcare systems should be designed to deliver equitable access to dedicated specialist centres for all patients living with psoriasis			
	The main barriers to equitable access to optimal psoriasis care are country-specific and operate at a national level. Therefore, they need to be addressed at a national level			
	In my role, I have a key role in ensuring equity of access to optimal care for all patients living with psoriatic disease			

Elevate quality of life measures as the most important outcomes	The negative impact on quality of life and daily functioning is the greatest source of the cumulative burden of disease on patients living with psoriasis	• Identify and prioritise the PROs/QoL tools that are more relevant to payors and commissioners to assess outcomes	• Ensure that patients' goals and burden are recognised and shared with their HCPs – integrate patient needs in decision making	
	QoL measures should be elevated as the most important clinical outcomes for patients with psoriasis assessed in clinical trials and clinical practice			
	There are validated QoL tools and measurements in existence that should be used consistently to assess the QoL of patients living with psoriasis			
Involving patients in patient-centred and personalised approaches to care.	Care for patients living with psoriasis should be built on a holistic approach that puts the patient at the very centre and actively encourages patients to engage in all aspects of their care	• Consider patients as partners in all decisions (including at the system level, drug development and RWE)	• Ensure that a holistic approach is followed to capture patient comorbidities • Educate patients around health-related concerns associated with psoriasis, increase awareness of disease, and encourage discussions around their unmet needs • Ensure patients are involved in research activities	• Support patient involvement in health authority meetings, legislative processes and regulatory decisions
	Patients living with psoriasis should play a valued role in decisions not only at the individual patient level but also at the system level			
	Patients are a valuable, under-used source of vital information, for example their experience of the patient pathway and administrative processes that determine medical care and treatment and how they could be improved, which could help elevate the SoC at the system (infrastructure) level			

Improve the relevance and reach of guidelines	Guidelines that integrate clinical data (both trial and real-world) with health economic data are lacking	• Gather RWD and health economic evidence to demonstrate cost-effectiveness of MDT working in the long-term • Utilise new technologies to capture evolving data sets and management	• Encompass patients' perspective, experiences, and listen to their voices – ensure patient involvement across the process	
	Standards of care in psoriasis would be elevated with the use of guidelines that consider clinical data, including real-world data, and health economic evidence			
	Measuring the real-world clinical and health economic value of treatments in psoriasis over time is critical to ensure that standards of care can be elevated			
	Standards of care would be improved if guidelines better reflected the need for a multidisciplinary/multi-stakeholder approach to the management of psoriasis			
	Dermatologists and rheumatologists should share the management of patients with psoriasis			
	Multidisciplinary guidance should be developed by a multidisciplinary team, including input from patients			
Education	Patients should have access to high quality, comprehensive disease information, that is available on demand in different formats with the opportunity to ask questions and seek clarification if required	• Enhance knowledge of the disease in primary care (e.g., GPs, nurses, community pharmacists, etc.)	• Educate patients and guide them to find robust and high-quality medical information • Support patient participation in educational activities	
	Enhanced education and awareness of psoriasis in general practice is needed to improve appropriate referral to a			

	dermatologist, timely diagnosis and earlier intervention through multidisciplinary, holistic care and effective treatments			
	Dermatologists should be aware of the spectrum of comorbidities and their impact on patients living with psoriasis, so that further specialist advice can be sought in a timely manner			
	Payors and healthcare professionals should better appreciate the total impact and cumulative disease burden posed by psoriasis over the lifetime of patients living with this disease			
Multistakeholder engagement	Multi-stakeholder initiatives are likely to be the most successful type of collaboration with the biopharmaceutical industry	• Take initiatives to engage industry in multistakeholder activities and data exchange	• Ensure that patient data/relevant outcomes are communicated back to patients	
	Engagement initiatives between payors, patients/patient groups and healthcare professionals that are focused on elevating standards of care in psoriasis can be supported by industry provided there are shared goals, clear governance and a sustained commitment from all parties			
	R&D efforts and real-world data generation initiatives would be of more value if input from patients/patient advocacy groups was routinely sought			
	Patients and patient advocacy groups are underutilised, their valuable and			

	necessary input into R&D and RWD generation is lacking, and industry could do more to support such activities			

GP, general practitioner; HCP, healthcare practitioner; MDT, multidisciplinary team; PRO; patient-reported outcome; QoL, quality of life; R&D, research and development; RWD, real-world data; RWE, real-world evidence; SoC, standard of care.