

A framework for improving the quality of care for people with psoriasis

European Psoriasis White Paper: A report developed by the European Expert Working Group for Healthcare in Psoriasis

Introduction

People with moderate to severe psoriasis in Europe are undertreated.¹ They are often kept on therapies for too long, despite them being ineffective.^{1,2} There is also enormous variation across Europe in the quality of care that people with psoriasis receive.^{3,4}

In July 2012, an expert working group, comprising clinicians and patient advocacy group representatives, published a European Psoriasis White Paper. The White Paper, published in the *Journal of the European Academy of Dermatology and Venereology (JEADV)*, identifies key issues affecting the quality of psoriasis care across Europe and sets out a framework of recommendations to improve the situation for patients.

This document provides a summary of those recommendations. Click here for the full Psoriasis White Paper:

http://onlinelibrary.wiley.com/journal/10.1111/%28ISSN%291468-3083/homepage/psoriasis_white_paper.htm

Or scan this QR code:



Promoting disease awareness and assessing the impact of psoriasis on quality of life

Psoriasis is more than just skin deep. In fact, it is a chronic, auto-immune disease affecting approximately 14 million people in Europe.⁵ Psoriasis can have a high, negative impact on a person's physical and psychological well-being, as well as a large economic impact on society. However, public recognition of these facts is lacking.

Recommended actions

- Healthcare organisations and governments should recognise psoriasis as a serious medical condition
- Government and industry should partner with patient groups and healthcare professionals, to develop educational campaigns to raise public awareness of psoriasis, and drive funding for disease management support programmes

Improving the development and use of treatment guidelines

Treatment guidelines can be an important tool for improving quality of care provided to people with psoriasis. However, a lack of national guidelines in some countries, and lack of consensus amongst those that do exist, can act as a barrier to improving outcomes. Limited awareness of guidelines, and time to discuss these with patients during consultations, can also have a negative impact on quality of care.

Recommended actions

- European bodies should work to raise awareness of guidelines across Europe, and encourage the development of national guidelines in countries which do not have them
- Healthcare organisations and healthcare professionals should ensure that adequate time is provided in consultations to discuss treatment guidelines with the patient

Promoting the use of assessment tools and defining treatment goals

A wide range of assessment tools are available to measure disease severity and outcomes in psoriasis, such as the Psoriasis Area and Severity Index (PASI), but these tools are sometimes used inconsistently in clinical practice. A lack of clear and appropriate treatment goals can also make it difficult to judge the success of a therapy.

Recommended actions

- Healthcare professionals and healthcare organisations need to actively engage in conversations with patients regarding definition of treatment goals and involve patients in decisions about their individual treatment plan
- Healthcare professionals and healthcare organisations should ensure that treatment goals are sufficiently flexible to allow incorporation of lifestyle factors into a patient's treatment plan
- Patient advocacy groups can help to promote awareness of the assessment tools available, and increase their use in clinics



"Early access to high-quality care is central to improving the long-term outlook for a person with psoriasis. We hope that this framework

will be pivotal in improving standards of psoriasis care across Europe."

Professor Matthias Augustin, Director, Institute for Health Services Research in Dermatology & Nursing, University Medical Center Hamburg, & Chair of the expert working group.



"Our hope is that the Psoriasis Mandate, which supports the recommendations made in the Psoriasis White Paper, will give patients the power

to ask for standards of care they rightfully deserve to manage this chronic & distressing condition."

Ottfrid Hillman, Former President, The European Umbrella Organisation for Psoriasis Movements (EUROPSO).



Improving access to appropriate therapy and ongoing care

Surveys have demonstrated that people with psoriasis do not receive the optimal care that is necessary to clear their skin symptoms, treat their disease and improve their quality of life.^{2,4,6,7} Comprehensive, multidisciplinary care is important for patients with psoriasis, in order to address the overall burden of the disease.

Recommended actions

- Healthcare organisations should ensure there is sufficient resource and investment to provide adequate access to care, especially for patients with moderate to severe psoriasis
- Healthcare organisations and healthcare professionals should provide ongoing and timely monitoring of treatment effectiveness
- Psoriasis should be managed in a multidisciplinary team setting

Defining the role of patient advocacy in psoriasis healthcare

With increasing demands for patient-centred approaches to healthcare, the role of patient advocacy groups is expanding. Patient advocacy groups can now be considered to represent patients' perspectives, and be an important contributor to healthcare guidelines and policy making.

Recommended actions

- Patients, healthcare professionals, patient advocacy groups and others involved in psoriasis care should seek to adopt a co-operative approach to achieve their common goals
- Greater collaboration between patient advocacy groups and European and national healthcare organisations should be sought to ensure that guidelines sufficiently reflect patients' needs
- Patient advocacy groups should strive to create patient-friendly versions of relevant guidelines to ensure that these documents can be understood by patients

The Psoriasis Mandate: your opportunity to get involved

Despite significant clinical advances in the field of psoriasis, people with this condition are still undertreated.

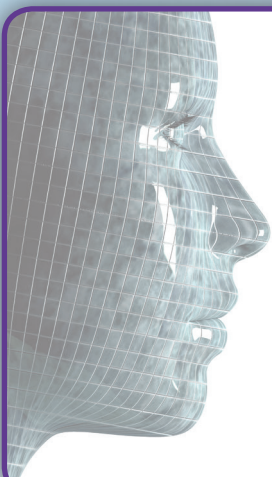
Therefore, there remains an ongoing need to raise awareness of psoriasis as a serious medical condition that can greatly impact on a person's quality of life.

As a result of the findings from the White Paper, the Psoriasis Mandate was launched in 2012 by the expert working group along with Janssen* and EUORPSO, to gain support for improved standards of care for each and every person living with psoriasis in Europe today. The Psoriasis Mandate provides an opportunity for the community at large, people with psoriasis and their healthcare professionals to pledge their support for the five key rights of people with psoriasis.

To pledge your support, you are invited to sign the Psoriasis Mandate:

www.psoriasis360.com/psoriasis-mandate

Or scan the QR code above.



The Psoriasis Mandate

I believe that each person living with psoriasis has a right to:

- ✓ Early and accurate diagnosis
- ✓ Access to a specialist for regular treatment review
- ✓ Access to effective treatment options
- ✓ Involvement and choice in a treatment plan with defined goals
- ✓ Understanding and support from society to live a normal life

* The Psoriasis White Paper and the Psoriasis Mandate are supported by Janssen, more specifically Janssen Pharmaceutica NV, Belgium.

References

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