



A plain language summary of what freedom from disease means to people with psoriasis according to doctors, nurses, and people with psoriasis

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Summary

What is this summary about?

This summary presents findings from recent research involving people with psoriasis, based on an article originally published in the *Journal of the European Academy of Dermatology and Venereology*.

Psoriasis is a condition that primarily affects the skin. However, it can also influence people's mental health, social activities, work, and relationships too. Current assessment tools used by doctors and nurses do not cover the complete experience of people with psoriasis, which often include other medical conditions and can leave these individuals feeling that treatment has not been successful. Researchers conducted a study in which people with psoriasis, doctors, and nurses were asked in virtual meetings and via questionnaires what freedom from disease in psoriasis means to them.

What were the results?

In addition to skin symptoms, the areas of mental health, well-being, treatment, and relationships with healthcare teams were found to be important aspects to be addressed.

What do the results of the study mean?

Focusing on all five aspects of freedom from disease will help people with psoriasis manage their psoriasis with confidence.

Who is this article for?

This article may be of interest to:

- People with psoriasis, their families, and carers
- Patient advocates
- Healthcare professionals who treat people with psoriasis, e.g., doctors, nurses, nurse practitioners, and physician assistants



What did this study look at?

Psoriasis is a chronic condition likely caused by the body's own natural defense system (immune system) leading to an excess of inflammation. The condition mainly affects the skin, causing areas to become red, itchy, and scaly.

Doctors usually assess how severe psoriasis is or how successful a treatment is based on clinical tools, such as doctor-reported measures of psoriasis severity, and patient-reported outcomes which are self-assessments from patients on how well they are doing.

- One clinical tool often used is the Psoriasis Area and Severity Index (PASI), which looks at both the severity of symptoms and the areas affected.
- A commonly used patient-reported outcome is the Dermatology Life Quality Index (DLQI), which looks at the impact of the disease on quality of life.

However, even if a person has a good score with these tools and the doctor may consider treatment a success, the person with psoriasis may still feel they are not completely “free” from the disease.

In this study called “**Freedom from Disease in Psoriasis**”, a group made up of people with psoriasis, nurses, and **dermatologists** worked together to understand what freedom from disease would mean for a person with psoriasis.



Dermatologists are specialist doctors who manage diseases related to skin, hair and nails.



Doctors



People
with psoriasis



Nurses

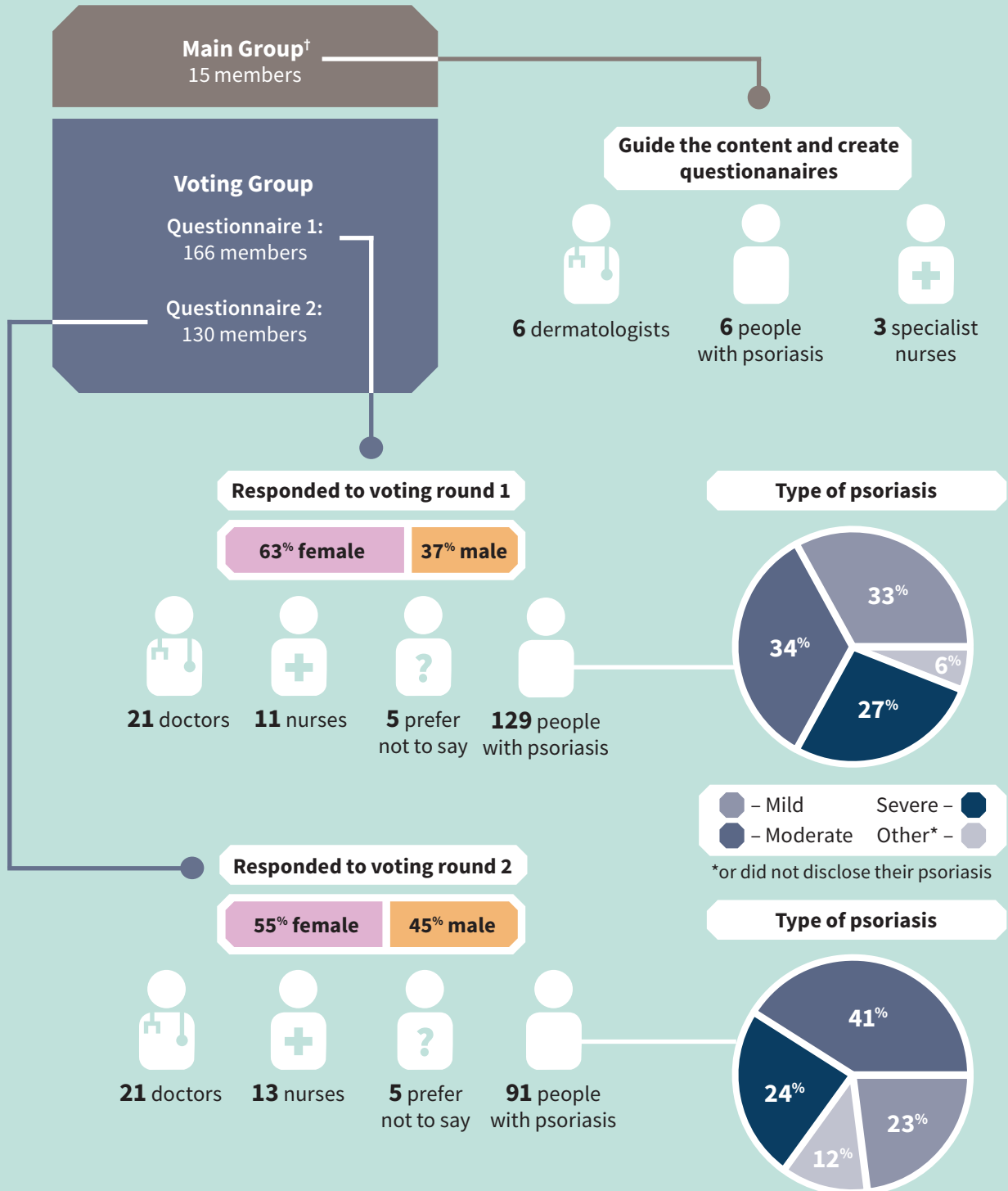
This research will help healthcare teams and people with psoriasis communicate better with each other about their treatment goals and work together to reach them.

Who took part in this study?

Two groups, comprising people from 15 different countries, took part in this European study:

- The main group consisted of 15 people who attended planning workshops, created the questionnaires, and were involved in guiding content throughout the study.
- A larger voting group was invited to respond to the questionnaires. The voting group consisted of 166 people who responded to the first questionnaire and 130 people who responded to the second, modified questionnaire.

Number of people with psoriasis, nurses, and dermatologists who took part in the study within the main group and two voting groups

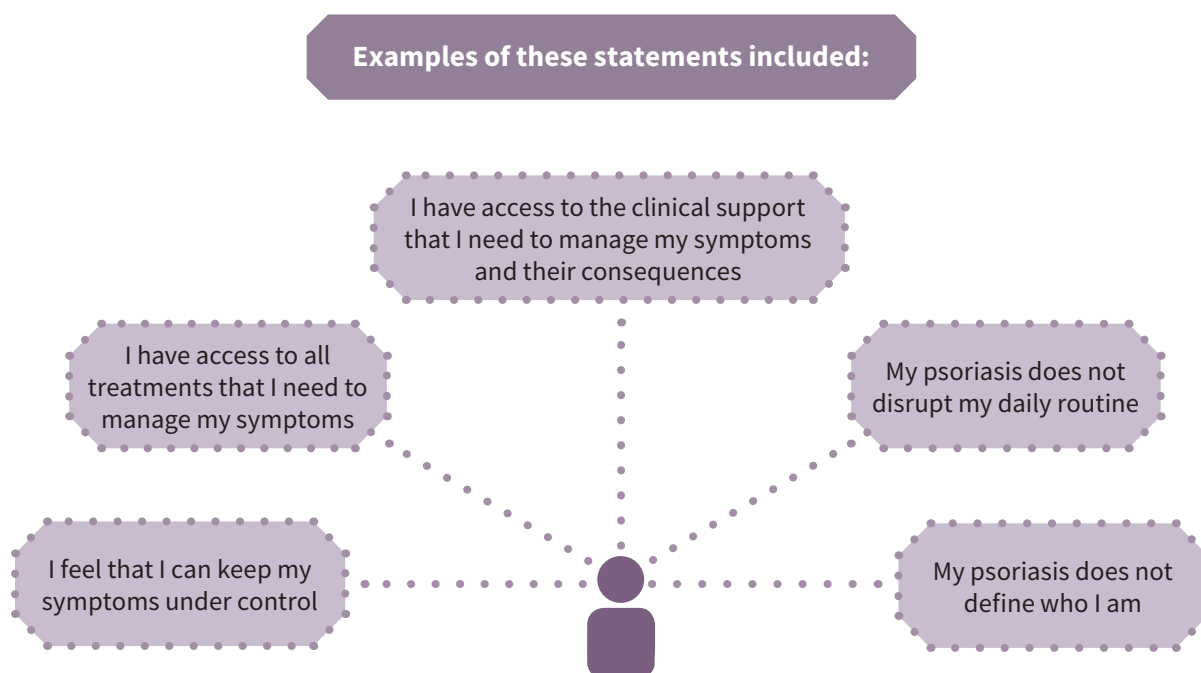


[†]Members of the main group were also invited to respond to the questionnaire.

How was the study carried out?

The main group took part in several online meetings and workshops to identify what aspects of care need to be addressed for people with psoriasis to feel “free” from disease.

Their experiences and opinions were used to create statements that described what “freedom from disease” means to people with psoriasis.



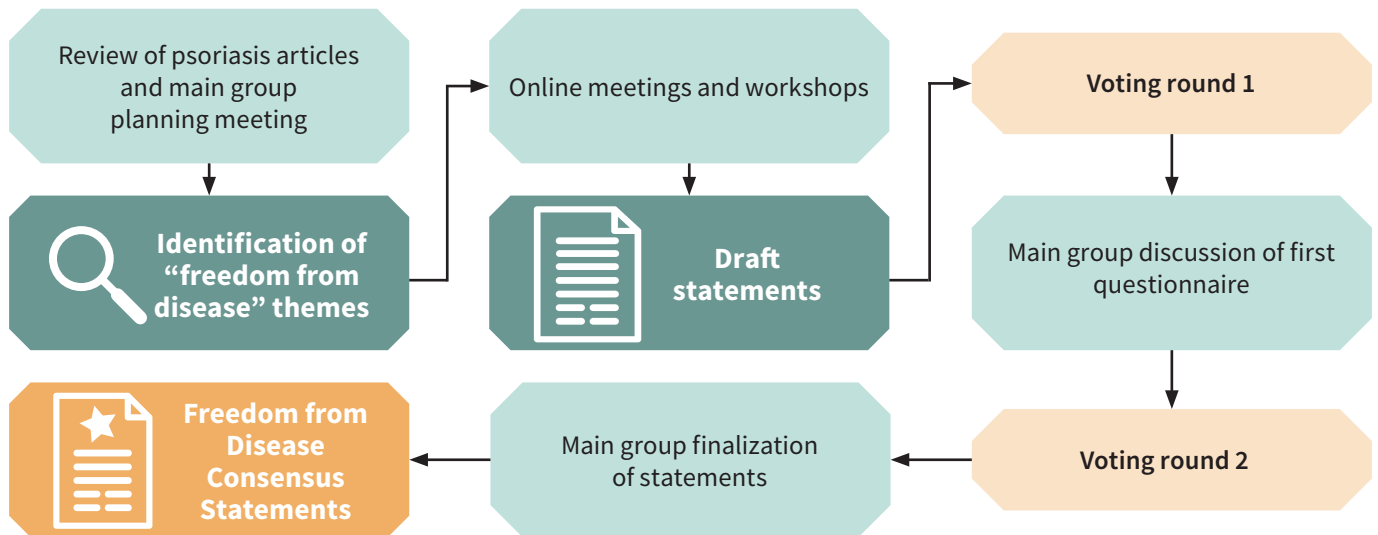
A questionnaire, including a total of **82 different statements**, was created and sent out to people in the voting group, asking them to score how important each statement was for achieving freedom from disease using a scale from 0 (not important) to 10 (very important). A total of **166 people responded**.

The responses were collected, and the main group discussed the results.

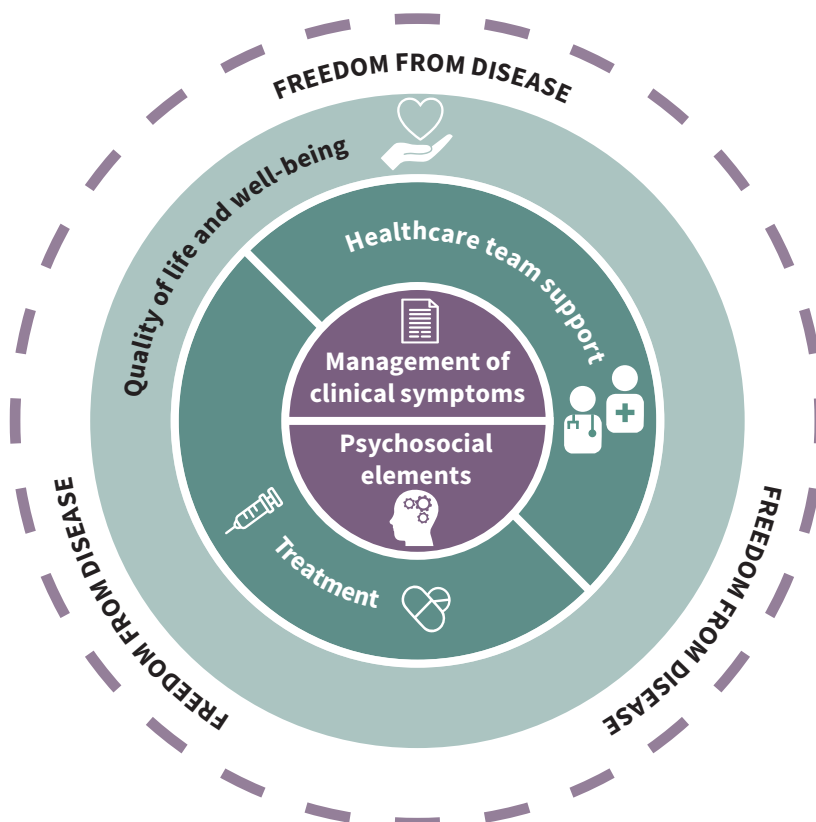
To further inform the final consensus statement, a second questionnaire was developed, that included the top five high priority statements and other statements considered of high importance by the main group from the first questionnaire, and sent out to the voting group. The second revised questionnaire included a total of **35 statements** and a total of **130 people responded**.

From these responses, the main group discussed the results and decided on the **final statements to define freedom from disease**. This included one overarching statement and five additional statements, one for each of the five aspects identified as important for achieving freedom from disease in psoriasis.

How the study was carried out and the final freedom from disease consensus statement achieved



Five main aspects of freedom from disease in psoriasis, how they fit together, and their overarching statement



Consensus statement

“Freedom from disease” is multifaceted with five core elements. Addressing all five offers individuals with psoriasis a restoration of normality; effective, lasting treatment to manage visible and non-visible clinical symptoms, eliminating the anxiety and fear of losing control, and resulting in no impact of disease owing to treatment management, with treatment meeting the individual’s needs and expectations. This reduces psychosocial burden, improving quality of life and well-being, and enabling life to be lived fully with the confidence that psoriasis will not disturb it.

What were the results of the study?

Freedom from disease in psoriasis can be divided into five main aspects



Management of clinical symptoms

- Clearance of all skin lesions (patches of damaged skin), especially those in sensitive areas of the body
- Being in control of non-visible symptoms



Psychosocial elements

- Chance to live a “normal life” without focusing on psoriasis
- Eliminating the anxiety and fear of losing control of the disease



Quality of life and well-being

- Psoriasis should not affect daily routines and relationships
- Live confidently without psoriasis impacting the patient's life



Treatment

- Confidence in long-term safety management
- Early access to optimal treatment
- No fear of side effects



Healthcare team support

- Good relationship with healthcare team
- Shared decision-making to agree on optimal treatment plan
- Open discussion on individuals' needs and treatment options in order to address individuals' expectations

These five aspects are interconnected. For instance, effective, long-lasting control of the symptoms of psoriasis can be achieved with optimal treatment and healthcare team support.

Furthermore, having these aspects in place will help reduce anxiety and fear of the condition, allowing people with psoriasis to achieve a better quality of life and well-being.

Addressing all five aspects of freedom from disease will help people with psoriasis manage psoriasis with confidence.

How does this research affect me?

By looking at the five aspects of care identified in this study, you can discuss with your healthcare team what freedom from disease means for you and use it to plan and monitor progress towards your treatment goals and needs.

Who sponsored this study?

This study was sponsored by Janssen.

Where can readers find out more about this study?

The full title of the original publication is “Freedom from disease in psoriasis: a Delphi consensus definition by patients, nurses, and physicians” and was published in the *Journal of the European Academy of Dermatology and Venereology*. You can read the full article here: <https://onlinelibrary.wiley.com/doi/10.1111/jdv.17829>

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Author contributions

All authors contributed to the conception of this plain language summary. All authors participated in the implementation of the work and discussion of the summary. All authors reviewed and approved the final submitted plain language summary.

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Full author disclosure information can be found in the original article.

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