

ORIGINAL ARTICLE

Freedom from disease in psoriasis: a Delphi consensus definition by patients, nurses and physicians

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Abstract

Background Physician-reported clinical outcome and quality of life (QoL) measures are currently used to assess outcomes and direct treatment of plaque psoriasis. However, people with psoriasis may have different criteria for judging treatment success.

Objectives To build a unified consensus on the definition of ‘freedom from disease’ from a European stakeholder group, including people with psoriasis, dermatologists and nurses.

Methods The modified Delphi consensus methodology was used to define ‘freedom from disease’, with a consensus group consisting of people with psoriasis, nurses and dermatologists. This methodology involved people with psoriasis during the entire process and consisted of a 15-member Facilitating Consensus Panel to drive the programme content and a larger Voting Consensus Panel to vote on defining ‘freedom from disease’. The Facilitating Panel agreed on disease domains, and aspects of each domain were put forward to the Voting Consensus Panel to establish relative importance. Following two voting rounds, a meeting was held to agree on a final consensus statement.

Results The Facilitating Panel consisted of six patient advocacy group representatives, three specialist nurses and six dermatologists. Voting rounds 1 and 2 were completed by 166 and 130 respondents from the Voting Consensus Panel, respectively. The outputs from both rounds of voting were similar, focusing on normality of living, symptom control, and a relationship of mutual respect and trust between the individual with psoriasis and their healthcare professional. The consensus statement emphasizes that ‘freedom from disease’ is multifaceted and includes the following domains ‘management of clinical symptoms’, ‘psychosocial elements’, ‘QoL and well-being’, ‘treatment’ and ‘healthcare team support’. ‘Freedom from disease’ means all aspects are addressed.

Conclusions Freedom from disease in psoriasis is a multicomponent concept including five main domains. This diverse and multifaceted patient perspective will help us to improve understanding of the outcomes of treatment interventions in people with psoriasis.

Received: 7 July 2021; Accepted: 3 November 2021

Conflict of interest

I. van Ee, A. Meyer and J. van der Zon had no conflicts of interest to declare. E. Deprez received consulting fees from Janssen. A. Egeberg received research funding from AbbVie, Bristol-Myers Squibb, Danish National Psoriasis Foundation, Eli Lilly, Janssen Pharmaceuticals, Kgl. Hofbundmager Aage Bangs Foundation, Novartis, Pfizer and Simon

Spies Foundation; received honoraria as a consultant and/or a speaker from AbbVie, Ammirall, Bristol-Myers Squibb, Dermavant, Eli Lilly, Galápagos NV, Galderma, Janssen Pharmaceuticals, LEO Pharma, Mylan, Novartis, Pfizer, Samsung Bioepis Co. Ltd., Sun Pharmaceuticals and UCB; received honoraria for participation in an advisory board with Samsung Bioepis Co. Ltd. M. Augustin received consultancy and/or speaker fees from and/or was an investigator for clinical trials sponsored by companies manufacturing drugs for psoriasis, including AbbVie, Ammirall, Amgen, Biogen, Boehringer Ingelheim, Celgene, Centocor, Eli Lilly, GlaxoSmithKline, Janssen-Cilag, LEO Pharma, Medac, Merck, MSD, Novartis, Pfizer, UCB and XenoPort. C. Conrad served as a scientific adviser and/or clinical study investigator for AbbVie, Actelion, Amgen, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene, Eli Lilly, Galderma, Janssen, LEO Pharma, Novartis and Pfizer; received consulting fees from AbbVie, Actelion, Amgen, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene, Eli Lilly, Galderma, Incyte, Janssen, LEO Pharma, MSD, Novartis, Pfizer, Samsung and UCB; received honoraria from AbbVie, Amgen, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene, Eli Lilly, Galderma, Janssen, LEO Pharma, Novartis, Pfizer and UCB; received payment for expert testimony from AbbVie, Celgene, Eli Lilly, Galderma, Janssen, LEO Pharma, Novartis and Pfizer; received honoraria for participation in advisory boards for AbbVie, Amgen, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene, Eli Lilly, Galderma, Janssen, LEO Pharma, MSD, Novartis, Pfizer and UCB; and served in a fiduciary leadership role for SSDV and ESDR. V. Corazza received grants and personal fees from Pfizer. L. Donati received grants and personal fees from UCB. J. Lambert received unrestricted grants from AbbVie, Ammirall, Celgene, Eli Lilly, Janssen-Cilag, LEO Pharma, Novartis and UCB; served as a speaker for AbbVie, Ammirall, Bristol-Myers Squibb, Janssen-Cilag, Pfizer and UCB; served as a consultant for AbbVie, Bristol-Myers Squibb, Celgene, Eli Lilly, Janssen-Cilag, LEO Pharma, Novartis and UCB. R. Lăpădatu received grants on behalf of her institution from AbbVie, Alliance, Healthcare Romania, Alvogen, Amgen Romania, AstraZeneca, BMS, Deyan, Kraft Medical, Farmexim, Farmexpert, Fildas Trading, Fresenius Kabi, Genesis Biopharma Romania, Genodynamic, GSK, Johnson&Johnson, Med Serv United, Merck Romania, MSD Romania, Novartis, Novo Nordisk, Oxygen Pharma, Pfizer, Pharmalink, Servier, SIEPCOFAR, Takeda, UCB, A&S Med Warehouse, Perfect Care Distribution, Rubicon Pharmaceuticals, York Farm and Worwag Pharma. C. Paul received research grants from AbbVie, Boehringer Ingelheim, Celgene, Eli Lilly, Janssen, Pierre Fabre, Sanofi and UCB; received personal fees from AbbVie, Ammirall, Amgen, Boehringer Ingelheim, Celgene, Eli Lilly, Janssen, LEO Pharma, Merck, Pierre Fabre, Pfizer, Regeneron, Sanofi and UCB. R. Penzer-Hick received consultancy fees from AbbVie. K. Stephen received consultancy fees and travel support from AbbVie, Ammirall, Janssen, LEO Pharma, Novartis and UCB; received speaking fees from AbbVie, Ammirall, Janssen, LEO Pharma and Novartis. A. Bewley received *ad hoc* honoraria or travel grants from AbbVie, Ammirall, Eli Lilly, Galderma, Janssen, LEO Pharma, Novartis, Sanofi and UCB.

Funding sources

This study was sponsored by Janssen. Medical writing and editorial support were provided by Cello Health MedErgy, funded by Janssen.

Introduction

Psoriasis is a chronic disease associated with high disease burden,^{1–4} and the impact of psoriasis on physical, social and psychological well-being is often underestimated.^{5,6} Psoriasis in areas such as the scalp, face, genitals, hands, feet and nails is more easily overlooked in clinical examination, and this type of underdiagnosed and undertreated psoriasis can have a substantial negative impact on the quality of life (QoL) of people living with the disease.^{3,7}

While the most well-known symptoms of psoriasis, such as scaling, itching and erythema are associated with the skin, the burden of the disease can go beyond the visible nature of plaques and lesions.³ People with psoriasis are at an increased risk of developing comorbidities such as cardiovascular and other diseases.³ Importantly, psoriasis can also affect mental health and have great impact on daily social activities and work, causing

people with psoriasis to feel fatigued, embarrassed, anxious and depressed. Stigmatization associated with the disease can leave individuals feeling isolated, frustrated and unattractive, putting strain on relationships with family and friends, their education and professional career.³

In clinical practice, psoriasis severity is usually defined and monitored by physician-reported clinical outcome measures, such as the proportion of body surface area (BSA) affected by psoriasis, the Psoriasis Area Severity Index (PASI) or one of several Physician Global Assessment measures.^{8,9} Although these measures may provide an objective and reproducible measure of psoriasis severity, none of these measures consider the perspective of people living with the disease,^{8,10,11} and there is a need to improve how individual patients' experiences are taken into account. Patient-reported outcome (PRO) measures, such as the Dermatology Life Quality Index (DLQI), along with active

listening to individual perspectives may help to reinforce the partnership between people with psoriasis and their healthcare professional (HCP).^{12,13} However, even after achieving treatment success as defined by physician or PRO measures, i.e. 75%/90% reductions in PASI, BSA < 1% and low DLQI scores, the individual with psoriasis may continue to have symptoms, such as itching or pain, which can negatively affect their QoL.^{9,12,14} This may lead them to feel that treatment success has not been achieved in a way that is meaningful to them.

Therefore, the impact of disease on people with psoriasis should be evaluated using a holistic approach, considering their QoL and psychosocial aspects, as well as any potential comorbidities. Treatment effectiveness should be assessed by understanding how the individual with psoriasis views treatment success, and how they would define effective disease management and 'freedom from disease' in relation to their own experience. Since the advent of very effective psoriasis medications, including biologics, there has been a growing interest in the concept of complete clearance of physical disease as defined by PASI score, but less attention as to what complete 'freedom from disease' means for people with psoriasis, despite previous expert recommendations that treatment policies should reflect the needs of people with psoriasis.^{4,15}

The concept of 'freedom from disease' represents a potential new treatment target in plaque psoriasis. This report describes the outcomes of a European study using modified Delphi methodology to achieve consensus from a multidisciplinary group in defining the concept of 'freedom from disease' in plaque psoriasis. The Delphi method has previously

been used to build consensus among physicians on other areas of clinical importance in psoriasis. However, most previous studies have generally not given a substantial share of voice to people with psoriasis or included them in the entire Delphi process.^{10,16,17}

A video summary of this publication is available as supplementary material (Video S1).

Methods

To define 'freedom from disease' for people with plaque psoriasis, a Delphi consensus methodology was used. The 'modified' Delphi method, which differs from the original Delphi method, includes a final meeting following the voting rounds, for expert interaction in the final phase of the consensus-building process.¹⁸ The aim was to produce an overarching consensus statement based on a set of core statements defining what constitutes 'freedom from disease' (Fig. 1).

A key fundamental in creating this programme was to ensure that people with psoriasis were given an equal share of voice in this consensus. As such, two panels, both consisting of people with psoriasis, nurses and dermatologists, were recruited. Dermatologists and nurses were selected based on their experience in psoriasis as assessed by metrics such as number of publications, citations, presentations and participation in the development of guidelines. Patients included in the panel were recruited through patient advocacy groups (PAGs). The aim was to recruit a panel that was diverse and geographically heterogeneous with members from a wide range of European countries. Initially, a Facilitating Consensus Panel was recruited to drive the content

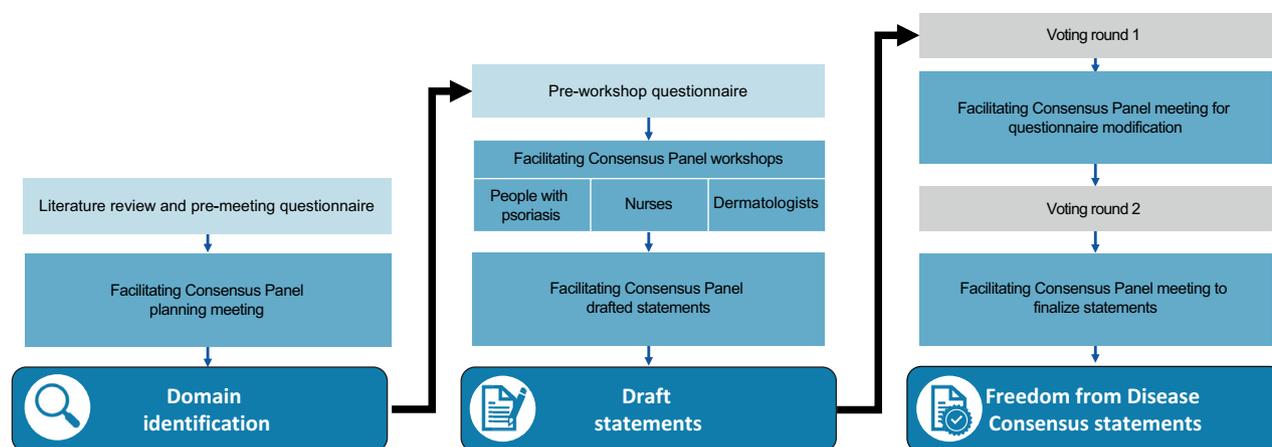


Figure 1 Modified Delphi methodology to build consensus on the definition of 'freedom from disease' for people with psoriasis. Detailed descriptions of the various stages of the consensus-building process are provided in the Appendix S1 (Supporting Information). For voting rounds 1 and 2, the full Voting Consensus Panel (which included the Facilitating Consensus Panel) was invited to participate in each voting round.

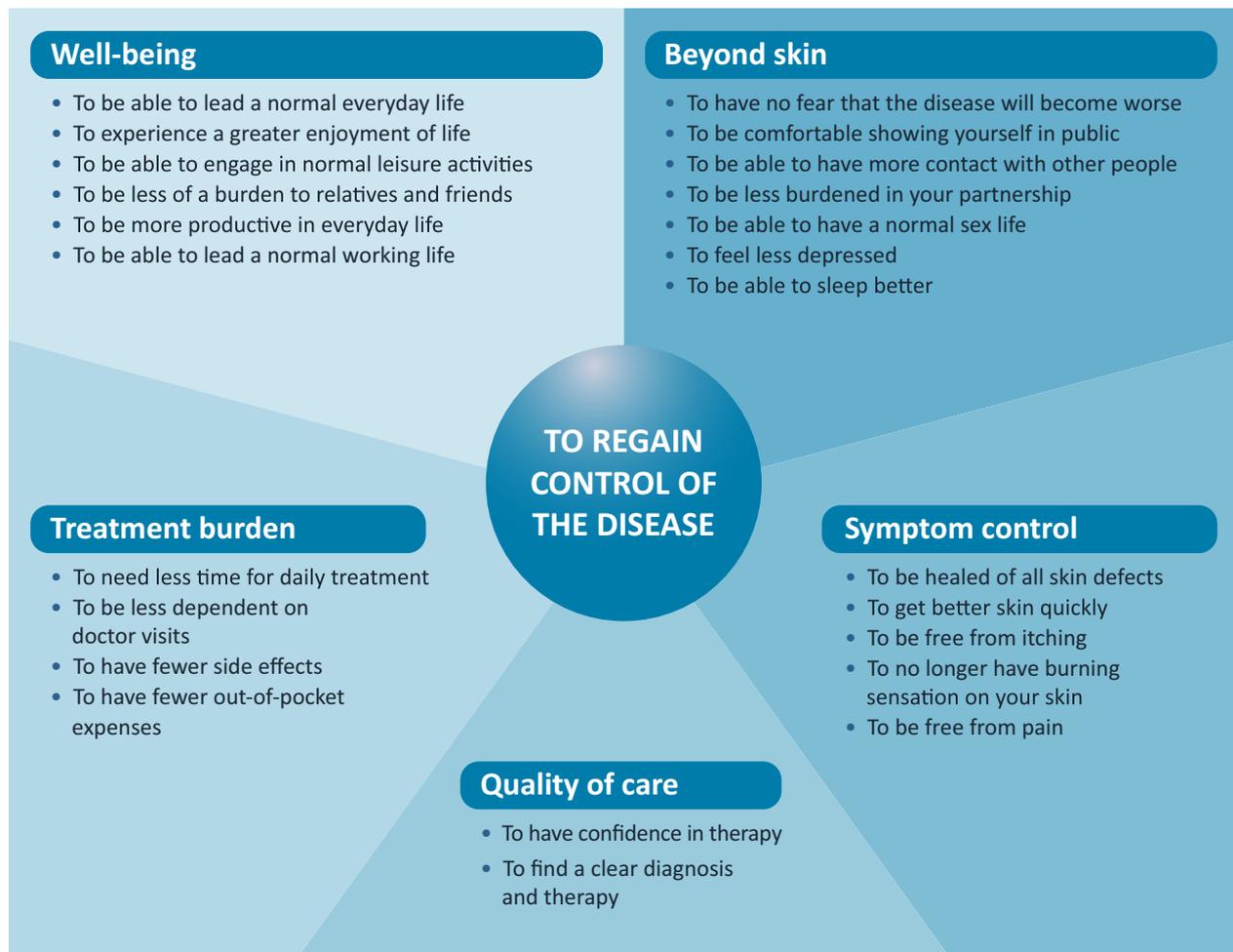


Figure 2 Planning meeting outputs: the five domains used to help guide and initiate the thinking of the Facilitating Consensus Panel.

of the programme. Subsequently, a larger Voting Consensus Panel was recruited whose role was to vote and provide consensus on the content produced by the Facilitating Consensus Panel. Members of the Facilitating Consensus Panel were included in the Voting Consensus Panel, which comprised dermatologists, nurses and people with psoriasis who were recruited through PAGs.

Further detailed information about the different stages and voting rounds that comprised the Delphi consensus process are shown in the Appendix S1 (Supporting Information).

Results

The Delphi consensus on ‘freedom from disease’ took place between 29 April 2020 (start of the consensus programme with the virtual planning meeting) and 12 February 2021 (meeting with the Facilitating Consensus Panel to finalize the consensus statement). The Facilitating Consensus Panel consisted of 15

members: six representatives from four different PAGs, three specialist nurses and six physicians (dermatologists).

Development of multi-dimensional domains

The literature review revealed several large-scale surveys that were used to provide insights into the aspirations of people with psoriasis for what ‘freedom from disease’ would mean to them.^{16,19,20} Key outputs from the virtual planning meeting are shown in Table S1 (Supporting Information). The outputs defined current limitations in the care of people with psoriasis, including the lack of assessments led by their views on their well-being and QoL. The meeting participants concluded that insights from people with psoriasis should be an important part of the consensus statements.

Based on the findings from the literature review and discussions during the virtual planning meeting, the following five domains were identified for further discussion: ‘symptom

Table 1 Baseline demographics and clinical characteristics of respondents completing voting rounds 1 and 2

Baseline demographics	Voting round 1	Voting round 2
Total responders	<i>N</i> = 166	<i>N</i> = 130
Age (years), <i>n</i> (%)		
<40	62 (37.3)	31 (23.8)
≥40	103 (62.0)	99 (76.2)
Female, <i>n</i> (%)	105 (63.3)	72 (55.4)
Designation		
Patients, <i>n</i> (%)	129 (77.7)	91 (70.0)
Nurses, <i>n</i> (%)	11 (6.6)	13 (10.0)
Dermatologists, <i>n</i> (%)	21 (12.7)	21 (16.2)
Preferred not to say, <i>n</i> (%)	5 (3.0)	5 (3.8)
Disease severity (for people with psoriasis)†		
Mild, <i>n</i> (%)	42 (32.6)	21 (23.1)
Moderate, <i>n</i> (%)	44 (34.1)	37 (40.7)
Severe, <i>n</i> (%)	35 (27.1)	22 (24.2)
Preferred not to say, <i>n</i> (%)	1 (0.8)	10 (11.0)
Other, <i>n</i> (%)	7 (5.4)	1 (1.1)
Country of residence, <i>n</i>		
Belgium	4	6
Denmark	2	2
France	2	2
Germany	34	30
Hungary	10	9
Italy	4	4
Netherlands	31	13
Portugal	1	1
Spain	2	3
Switzerland	1	1
UK	5	6
Romania	48	34
Poland	16	14
Croatia	3	3
Other‡	2	1
Preferred not to say	1	1

†Disease severity was based on the perception of the respondent.

‡Countries other than those listed in the table above: the USA and Ireland.

control', 'beyond skin', 'well-being', 'quality of care' and 'treatment burden'. An overview of these domains and their components are represented visually in Fig. 2. The domains were incorporated into the preworkshop questionnaires (Table S2, Supporting Information). It was also agreed that the final consensus should take the form of statements based on these five themed domains, plus one overarching statement.

Workshop outputs

During the online workshops for dermatologists, nurses and people with psoriasis/representatives from PAGs, the panellists shared their personal experiences of living with and/or managing psoriasis. The insights from the three workshops were collected and analysed, and the main conclusions are shown in Table S3

(Supporting Information). Open-ended questions were asked at the workshops to prompt the panellists to provide unbiased answers (Table S4, Supporting Information).

Consensus statement development

Preliminary draft statements developed by the Facilitating Consensus Panel were grouped together into five themes based on the five domains that were identified in the virtual planning meeting and the outcomes of the three workshops. The draft statements are listed in Table S5 (Supporting Information).

Voting panel outputs

A total of 166 and 130 respondents, more than 70% of whom were patients, completed rounds 1 and 2 of the voting, respectively. The Voting Consensus Panel covered a broad geographical area, with participants from 15 different European countries. Their demographic characteristics, including age, sex, country of residence and the ratio of people with psoriasis, physicians and nurses are presented in Table 1.

The top five high priority statements for each of the five domains with an average score of 8–10 during voting round 1 are presented in Fig. 3. Following the initial round of voting, the wording of some of the top five statements was improved by the Facilitating Consensus Panel before being included in the next round of voting, and some additional statements that were considered as highly important by the panel were included for voting round 2. Voting consensus panel respondents were presented with these modified statements and asked to select the top three that they considered to be the most important in defining 'freedom from disease'. The revised statements as presented to the Voting Consensus Panel are shown in Table S6 (Supporting Information). The statements that were voted 'top 3' during voting round 2 and their ranking, based on how many respondents rated them most important in each domain, are presented in Fig. 4.

Finalized consensus statement

The final overarching consensus statement to define the concept of 'freedom from disease' and final statements for each subsection was developed by the Facilitating Consensus Panel during a virtual meeting based on the results from the second voting round; these final statements are shown in Fig. 5. The Panel agreed that effective symptom control focused on clearance of skin lesions will help to reduce the psychosocial burden associated with psoriasis. In order to achieve control of skin symptoms and associated psychosocial burdens, optimized treatment and healthcare team support are required. When all these aspects are achieved, patients will achieve a high level of QoL and well-being, having full control of their disease and enabling them to live confidently without psoriasis impacting their lives. Therefore, together, these aspects define freedom from disease in psoriasis.

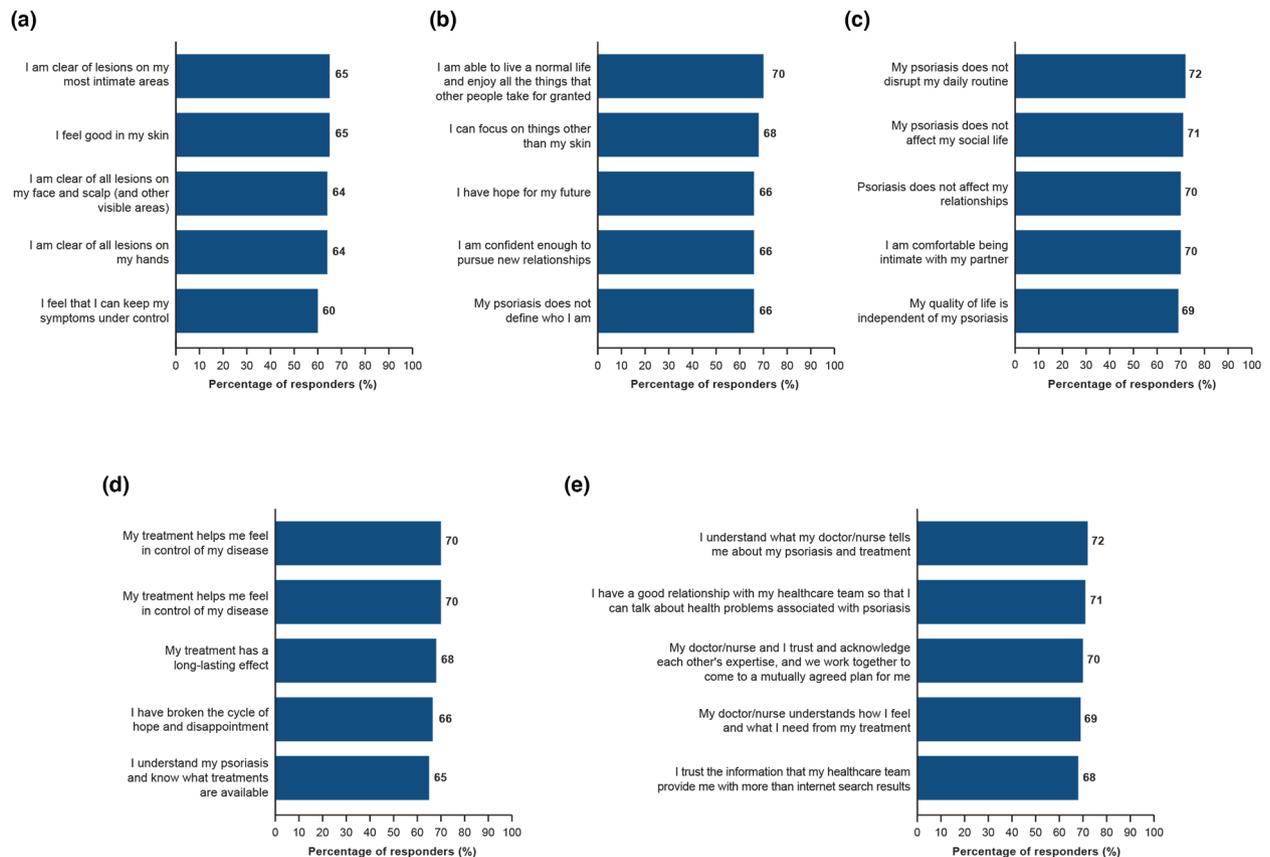


Figure 3 Delphi questionnaire round 1 output: top five high priority statements scoring 8–10 for (a) Management of clinical symptoms; (b) Psychosocial elements; (c) QoL and well-being; (d) Treatment; (e) Healthcare team support. QoL, quality of life. Number of responders (*n*), (a) *n* = 166; (b) *n* = 146; (c) *n* = 135; (d) *n* = 126–127; (e) *n* = 116.

The final overarching consensus statement was defined by the Facilitating Consensus Panel as follows: “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 QoL and well-being, and enabling life to be lived fully with the confidence that psoriasis will not disturb it’.

Discussion

The outputs of this European study using a modified Delphi methodology to define and achieve consensus on the concept of ‘freedom from disease’ present a potential new treatment target. The consensus statement defined by the Facilitating Consensus Panel emphasizes that ‘freedom from disease’ is multifaceted and includes the following five domains:

‘management of clinical symptoms’, ‘psychosocial elements’, ‘QoL and well-being’, ‘treatment’ and ‘healthcare team support’. ‘Freedom from disease’ means that all these aspects are sufficiently addressed.

The Delphi methodology used here aimed to develop a broad consensus. The panel members included people with psoriasis, dermatologists and nurses involved in the treatment of psoriasis. Moreover, a rigorous methodology was implemented, with multiple meetings, including separate meetings for the different specialist panel members. This enabled us to develop an iteratively modelled and precise consensus, which had the direct input and agreement of people living with psoriasis, as well as those involved in their treatment. This Delphi consensus is the first in its field to include people with psoriasis on the Facilitating Consensus Panel and to involve them at every stage of the consensus decision process. Considering the point of view of both patients and HCPs provides a more accurate perspective on the concept of ‘freedom from disease’. Specifically, it includes the wider needs of people with psoriasis, from a standpoint that has been

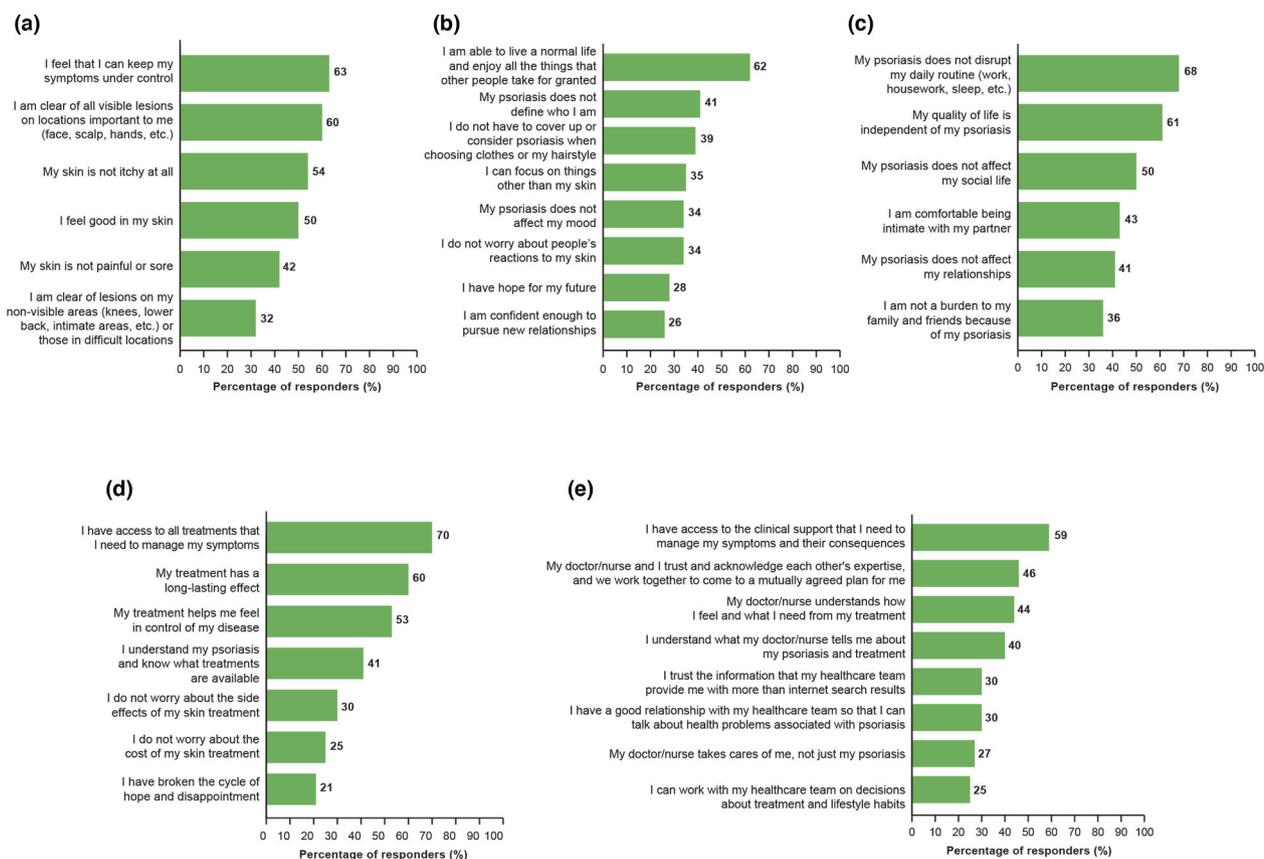


Figure 4 Delphi questionnaire round 2 output: statements voted 'top 3' from (a) Management of clinical symptoms; (b) Psychosocial elements; (c) QoL and well-being; (d) Treatment; (e) Healthcare team support. QoL, quality of life. Number of responders (n), (a) $n = 130$; (b) $n = 119$; (c) $n = 111$; (d) $n = 109$; (e) $n = 105$.

directly informed by feedback from people with psoriasis as part of this novel Delphi consensus. In addition, this Delphi consensus provides a multinational point of view on 'freedom from disease' with input from participants from 15 countries across Europe.

The outputs from both rounds of voting highlighted areas of importance—normality of living, symptom control, and a relationship of mutual respect and trust between the individual with psoriasis and their HCP. In both voting rounds, there was a strong focus on the importance of being clear of visible lesions and the perception of being in control of symptoms. Psychosocial statements were focused on individuals being able to live a 'normal life' and the wish to not be defined by their psoriasis, while the treatment subsection focused on the desire to have full access to, and understanding of, available treatments. The relationship between the individual with psoriasis and their HCP was also considered important in both voting rounds, with a stated requirement for their HCP to understand the needs of the individual with psoriasis; mutual respect and trust were also highly regarded.

It is clear from the finalized consensus statements that the psychosocial burden of living with psoriasis is a major consideration when managing the disease, and that full lesion clearance in significant body areas is key to people with psoriasis feeling that their disease is under control. Having control of their disease is also central to the QoL and well-being of people with psoriasis, and this can be achieved by ensuring that they have access to comprehensive information on the available treatments and by building a relationship of mutual trust and respect between the individual with psoriasis and their HCP.²¹

Finally, the overarching consensus statement helps us to understand that the concept of 'freedom of disease' is multifaceted, with all five themes needing to be addressed to allow the individual with psoriasis to feel that they have fully reached this state. Although not specifically addressed in this consensus statement, 'freedom from disease' in psoriasis also implies freedom from any potential comorbidities. Psoriatic arthritis, inflammatory bowel disease, psychiatric disorders and uveitis have traditionally been associated with psoriasis. More recently, metabolic

- **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.
- **QoL AND WELL-BEING**
 For individuals, control of psoriasis means that their daily routine at home and at work, their relationships and social life, and intimacy, are all returned to normal. This enables them to live confidently, without psoriasis impacting their life.
- **HEALTHCARE TEAM SUPPORT**
 To address individual expectations and all elements of living with psoriasis, an effective healthcare professional and patient relationship is essential. This is based on trust, time spent on individual needs, open discussion of treatment options, and shared decision making to agree the optimal treatment plan.
- **TREATMENT**
 Early access to optimal treatment enables effective symptom control. This helps eliminate anxiety and fear due to loss of control, while providing confidence in long-term safe management without the worry of side-effects, and relief from all symptoms of disease.
- **PSYCHOSOCIAL ELEMENTS**
 The psychosocial burden of living with psoriasis can be overwhelming, resulting in anxiety and recurrent fear of losing control, leading to reduced confidence and hope, and isolation. These feelings can persist even when existing symptoms are controlled.
- **MANAGEMENT OF CLINICAL SYMPTOMS**
 Effective symptom control should include clearance of all lesions, particularly those important to individuals, such as those most visible or in sensitive regions. It must also tackle non-visible symptoms such as pain, itch and soreness.

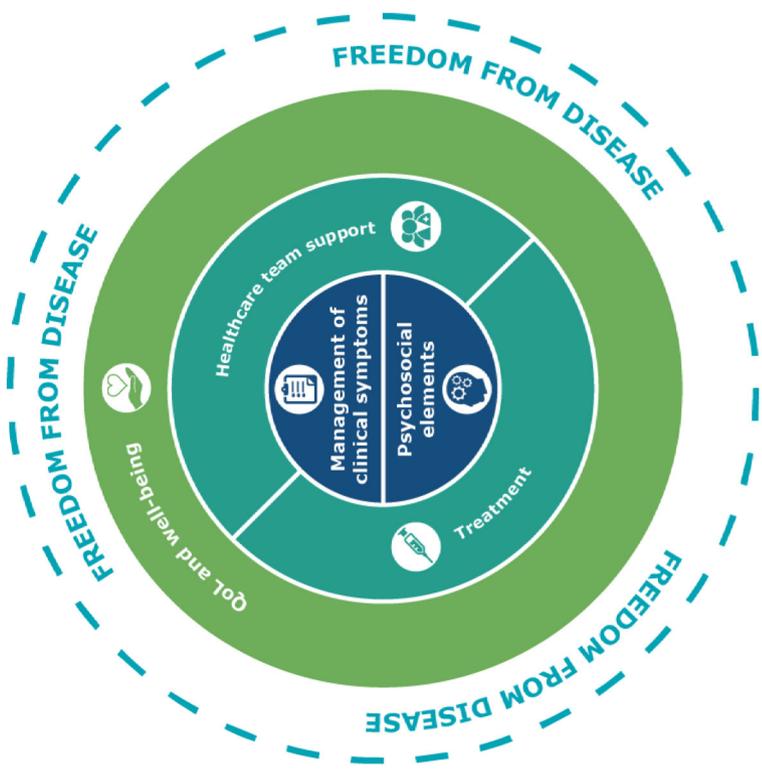


Figure 5 Final Delphi panel meeting: a consensus statement.

syndrome, cardiovascular disease and other conditions have also been linked with psoriasis.²² Improving the care and treatment of comorbidities in addition to addressing psoriasis specifically will help people to maintain optimal QoL.

While existing physician-reported and PRO measures can help to evaluate psoriasis disease burden, QoL and the treatment preferences of people with psoriasis, these existing outcome measures have limitations and do not always adequately capture their needs and priorities.²³ There is increasing use of consensus meetings to identify and determine appropriate ways of assessing all relevant disease domains. For instance, the HOME consensus meeting for atopic dermatitis identified four core disease domains to be assessed in clinical trials ('clinician-reported signs', 'patient-reported symptoms', 'health-related QoL' and 'long-term control') and provided recommendations for appropriate outcome measures to assess the various domains.²⁴ This suggests that consensus meetings can be effective in determining ways of appropriately assessing all relevant aspects of skin diseases.

'Freedom from disease' represents a new treatment target in psoriasis that goes beyond traditional concepts of clinical remission and QoL measures to include the goals of people with psoriasis, nurses and physicians. It also includes the wider needs of people with psoriasis, from a standpoint that has been directly informed by feedback from people with psoriasis as part of this novel Delphi consensus. This supports recommendations stated in the WHO Global report on Psoriasis, which highlights the need for people-centred care, taking into account not only the issues related to their psoriasis, but also other aspects related to their health and well-being.³ PAGs have been involved in this study from the very start, from drafting the questionnaire statements using verbatim responses of people with psoriasis in the core panel to finalizing the consensus based on their feedback, thus facilitating an approach centred on the needs of people with psoriasis. In addition, this Delphi consensus provides a multinational point of view on 'freedom from disease' with input from people with psoriasis, nurses and dermatologists from 15 countries across Europe.

In conclusion, '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 QoL and well-being, and enabling life to be lived fully with the confidence that psoriasis will not disturb it.

Acknowledgements

The authors would like to thank Elaine Anderson (nee Davis), Ewa Gielo, Federico Palomar Llatas, Barbara Page, Iain Bowman, Professor Luis Puig, Professor Wiebke Ludwig-Peitsch, Dr

Pierre-Dominique Ghislain, Dr Sascha Gerdes, Professor Brian Kirby, Professor Peter van de Kerkhof, Dr Kasper Hjuler, Professor Cairiona Ryan, Professor Lajos Kemény, Professor Tiago Torres, Dr Andrea Chiricozzi, Professor Rolland Gyulai, Professor Stefano Piaserico, Dr Lynda Grine, Professor Thomas Luger, Professor Julien Seneschal; in addition to members of the Deutscher Psoriasis Bund (DPB), Fondazione Natalino Corazza, Psoriasispatiënten Nederland (PN), Asociația Pacienților cu Afecțiuni Autoimune (APAA), Društvo Psorijatičara Hrvatske, Association of Hungarian Psoriasis (MPKE) and Amicus Foundation for their participation in voting on the Delphi consensus. Editorial and medical writing support were provided by Cello Health MedErgy and funded by Janssen.

Role of the sponsor

This project is part of an initiative by Janssen aimed at assessing different aspects of psoriasis treatment, with the focus of the current project being on building a consensus definition of 'freedom from disease' for people with psoriasis. Janssen engaged the support of Cello Health MedErgy in recruiting a multidisciplinary consensus panel; facilitating the planning meeting; developing materials, including preread meeting content, feedback forms/questionnaires, open-ended questions and statement development tools to support the Delphi process; collating anonymous responses to online polls, surveys and questionnaires for review/discussion by the consensus panel; and in developing this manuscript.

Data availability statement

The data that support the findings of this study are available from Cello Health MedErgy upon request (CommsMe-JanssenDermatology@ch-medergy.co.uk).

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Supporting information

Additional Supporting Information may be found in the online version of this article:

Table S1. Key conclusions from the virtual planning meeting.

Table S2. Planning meeting pre-meeting short online survey for patients, nurses and physicians.

Table S3. Workshop outputs: key conclusions from the workshops for people with psoriasis, nurses and physicians.

Table S4. Workshop questions for people with psoriasis, nurses and physicians to determine experiences of living with and/or managing psoriasis.

Table S5. Draft statements: thematically grouped statements included in Delphi questionnaire round 1.

Table S6. High priority statements: top five statements included in Delphi questionnaire round 2.

Table S7. Pre-workshop questionnaires for people with psoriasis, nurses and physicians to determine experiences of living with and/or managing psoriasis.

Appendix S1. Methodological details of the Delphi consensus process.

Video S1. Freedom from disease in psoriasis: a Delphi consensus definition by patients, nurses and physicians.