Vitiligo International
Patient Organizations
Committee

Rewriting the vitiligo patient experience: minding the gaps of the vitiligo pathway

An expert consensus paper

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MEP Foreword

Chronic skin diseases are, by their very nature, visible.

So why, despite the significant impact they have, are those living with these diseases left to feel unseen?

Around 185 million Europeans are affected by skin diseases, with nearly one in two reporting having suffered from at least one dermatological issue in the past 12 months.

Of these conditions, vitiligo stands out as a chronic skin disease that not only alters physical appearance, but also significantly impacts the emotional and social well-being of those living with it.

In order to understand the daily challenges faced by people living with vitiligo, we must first be frank about the reality that many face across Europe. They live with a condition that is often misunderstood and underestimated, leading to the all-too-common misconception that it is “just” a cosmetic issue.

That, however, is simply not the case.

Frequent isolation and a lack of support in relation to the disease can serve to exacerbate mental health issues such as anxiety and depression.

It is of the vital importance for us, as policymakers, to acknowledge these challenges and collaborate with all relevant stakeholders with a view to enhancing the patient pathway, from accurate diagnosis to timely treatment and social acceptance.

The European Union has a history of driving action in specific disease areas such as cancer, rare diseases and, more recently, cardiovascular diseases – but we can do more. To best address the unmet needs of people with chronic skin conditions, we should pilot and support initiatives to improve understanding, establish excellence in diagnosis and care, and focus on their co-morbidities with mental disorders.

Although healthcare remains primarily a national competence, there are still important initiatives that can be undertaken at an EU level to make a meaningful difference. Under the Non-Communicable Diseases Roadmap, we can improve the understanding, diagnosis and care of vitiligo.

This White Paper on ‘Rewriting the vitiligo patient experience’ comes at a welcome time, presenting practical solutions that require thorough discussions and decisive action during this parliamentary mandate.

The proposals outlined not only highlight the challenges faced by people living with vitiligo, but also provide actionable steps for policymakers, healthcare professionals and other stakeholders to collaborate effectively. Engaging with these recommendations will enable us to initiate meaningful policy changes that can significantly enhance the quality of life for the Europeans affected by this condition.

Therefore, I extend my congratulations to all the stakeholders involved in the development of this important document. Together, we can foster a more inclusive society that not only recognises vitiligo as a serious health issue, but also actively works towards eliminating the misconceptions and stigma associated with it.

Let us join forces to advance positive change, ensuring that people living with vitiligo receive the support they need to live full and rewarding lives.

MEP Oliver Schenk

Steering Committee Foreword

What do you think of when you think of vitiligo?

Despite the prevalence of the chronic disease, there is a chance that what you think is only part of the reality.

Misunderstood and misrepresented, healthcare professionals and decision-makers often address it superficially with fragmented approaches, frequently leaving patients alone to navigate the complexities of securing a confirmed diagnosis and understanding their treatment options.

This lack of support causes considerable emotional and social challenges to those living with vitiligo. The stigma associated with its unique appearance can lead to significant psychological distress, further isolating people and complicating their pathway towards effective treatment and acceptance within society.

In this context, with the support of Incyte, a Steering Committee was established with the mission of identifying common challenges faced by people living with vitiligo along the care pathway, and propose solutions that, if implemented, will improve patient outcomes and quality of life.

This paper is the result of a collaborative effort and would not have been possible without the support of a Scientific Working Group and a Patient Working Group. The contributions of each member have been invaluable as we strive to ensure people have an improved experience, better health outcomes and quality of life across Europe

However, to achieve this objective, we must actively involve policymakers in discussions to build collaboration on policies that address the full spectrum of needs.

From correcting existing misconceptions to ensuring equal access to treatment options and psychological support, we cannot do this alone. People living with vitiligo across the EU and UK face shared challenges, underscored by the need for unified solutions. This White Paper focuses on actions that can be adopted either at the EU level or through regional collaboration to complement strategies that need to be developed and implemented at national level.

With new leaders at the European Union level, it is essential that they recognise vitiligo and other chronic autoimmune skin disorders as an overlooked category of non-communicable diseases that requires immediate consideration and action. Fostering a deeper understanding and adopting a more comprehensive approach is key to ensuring that vitiligo is treated with the same urgency and care as other serious medical conditions, a necessity that should be mirrored in policy priorities.

In our capacity as members of the Steering Committee, we set out to chart the unmet needs of the patient community, but also the role of relevant stakeholders in making a transformative change towards better patient outcomes.

This White Paper presents a snapshot of those findings, and the current gaps experienced by people living with vitiligo in the selected countries. It outlines solutions and recommendations that have been collaboratively developed and endorsed by all stakeholders involved in this ambitious project.

It is crucial to eliminate the notion that vitiligo is simply about losing colour, and to promote recognition of its profound impact on people's lives – and that is what this White Paper sets out to achieve.

Steering committee

Professor Dr Nanja van Geel
Professor Dr Thierry Passeron
Mr Jean-Marie Meurant

Introduction

What is vitiligo?

This may seem like a simple question, but the results of this paper tell a different story, one of a lack of consensus on the severity, treatment and even the legitimacy of vitiligo ***as an autoimmune skin disorder****.*

It is one characterised by the loss of melanocytes. This results in white patches of skin[1]. It is estimated to affect 0.5%–2% of the global population and is the most common depigmenting skin disease.[2,3] In Europe, prevalence is estimated to be less than 1%, ranging from 0.2 to 0.8%.[4,5] Vitiligo impacts both men and women of all ages equally, with the onset of the disease typically occurring by the age of 30. However, initial symptoms can also appear later in life.[6,7,8]

It is one disease that can lead to others. One linked to a higher occurrence of associated health conditions, with the most frequent being thyroid disease, as well as psoriasis, type 1 diabetes mellitus, rheumatoid arthritis and alopecia areata, amongst others.[9]

It reaches beyond skin deep. Vitiligo is associated with significant quality-of-life (QoL) impairment in routine activities, employment and psychosocial health.[10,11] For example, one study found that vitiligo had an impact on one third of participants' emotional well-being, including self-esteem and stigma. Moreover, half of patients across Europe have symptoms of moderate-to-severe depression.[12] Those with visible lesions, such as on the face and hands, are more likely to experience depressive symptoms than those with lesions on less-visible areas of the body.[13] In Europe, 45% of patients have lesions covering at least 5% of their total body surface area.[14]

It disrupts lives. Vitiligo has a great impact on people's daily activities, from clothing choices, to attending social activities and exercising.[15] At global level, around 1 in 4 patients said vitiligo affected their career choices, while 1 in 2 people believe that vitiligo has slowed down their career progression.[16]

It is an economic burden. The condition has been found to entail considerable direct and indirect costs, as confirmed by a study which found 44.5% of patients living with vitiligo in Europe found the cost of non-reimbursed therapies discouraging.[17]

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[1] Rodrigues M, et al. *J Am Acad Dermatol.* 2017;77(1):1-13.
[2] Bergqvist C, Ezzedine K. Vitiligo: A Focus on Pathogenesis and its Therapeutic Implications. *J Dermatol.* 2021;48(3):252-270
[3] Kruger C, Schallreuter KU. *Int J Dermatol.* 2012;51(10):1206-1212
[4] Richard MA, Paul C, Nijsten T, et al. Prevalence of most common skin diseases in Europe: a population based study. *J Eur Acad Dermatol Venereol JEADV.* 2022; 36(7): 1088-1096.
[5] Mohr N, Petersen J, Kirsten N, et al. Epidemiology of vitiligo – a dual population-based approach. *Clin Epidemiol.* 2021;13:372-382.
[6] Ezzedine K, et al. *Lancet.* 2015;386(9988):74-84.
[7] Talsania N, et al. *Clin Exp Dermatol.* 2010;35(7):736-739.
[8] Radtke MA, et al. *Br J Dermatol.* 2009;161(1):134-139.
[9] Dahir AM, Thomsen SF. *Int J Dermatol.* 2018;57(10):1157-1164.
[10] Morrison B, et al. *Br J Dermatol.* 2017;177(6):e338-e339.
[11] Silverberg JI, Silverberg NB. *JAMA Dermatol.* 2013;149(2):159-164.
[12] Bibeau K, et al. Mental Health and Psychosocial Burden Among Patients Living With Vitiligo: Findings from the Global VALIANT Study. Presented at: Maui Derm for Dermatologists, 24 January 2022, Maui, HI.
[13] Grimes PE, Miller MM. Vitiligo: Patient Stories, Self-Esteem, and the Psychological Burden of Disease. *Int J Womens Dermatol.* 2018;4(1):32-37.
[14] Bibeau K, et al. Exploring the Natural and Treatment History of Vitiligo: Findings from the Global VALIANT Study. Presented at: Maui Derm for Dermatologists, 24 January 2022, Maui, HI.
[15] Bibeau K, et al Mental Health and Psychosocial Quality-of-Life Burden Among Patients With Vitiligo: Findings From the Global VALIANT Study. *JAMA Dermatol.* 2023;159(10):1124-1128.
[16] Bibeau K, et al. Mental Health and Psychosocial Quality-of-Life Burden Among Patients With Vitiligo: Findings From the Global VALIANT Study. *JAMA Dermatol.* 2023;159(10):1124-1128.
[17] Ezzedine K, Harris JE, Bibeau K, et al. Treatment Burden Among Patients With Vitiligo: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1402.

It is challenging to diagnose. Varying patterns of lesional spread and progression can result in vitiligo being misdiagnosed as other skin conditions – approximately 3 in 7 people living with vitiligo in Europe have experienced misdiagnosis.[18]

Approach to treatment remains inconsistent. Having a correct diagnosis does not necessarily enhance the experience of those living with vitiligo. 65% of vitiligo patients in Europe were told that their condition cannot be treated completely, and 17% of patients did not receive any treatment whatsoever.[19,20] Moreover, at the global level, nearly 45% of patients reported having given up on seeking effective treatment for vitiligo.[21] This suggests that for many patients, the best possible result is often acceptance of their condition, rather than alleviation of symptoms.

These are the challenges – so what is needed?

Considering these unmet needs, the current White Paper has been developed to raise awareness of, and provide a snapshot into, the challenges that patients face along the care pathway, focusing on awareness and pre-diagnosis, diagnosis and referral, treatment management and follow-up and access to treatment. Given that acceptance is not a solution that works for everyone living with vitiligo, and adequate treatments in line with people's needs are key, the current White Paper also proposes EU-wide and national policy solutions that can enhance patient care and outcomes.

People living with vitiligo share common challenges with those living with other conditions such as chronic skin diseases and atopic dermatitis, that are better known due to community advocacy and policy support.[22,23] These policy-focused initiatives have led not only to increased awareness, but they also serve as a crucial bridge between clinical evidence and policy action, effectively communicating the potential solutions for those within the dermatological community to those in positions to make meaningful change.

Above all else, this White Paper intends to further consolidate the evidence on the collective unmet needs of this neglected patient population and request the right to be heard in their specific asks.

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[18] Bibeau K, Harris J, et al. Diagnosis and Management of Vitiligo From the Perspectives of Patients and Healthcare Professionals: Findings From the Global VALIANT Study. Presented at: Maui Derm for Dermatologists, 24 January 2022, Maui, HI.

[19] Bibeau K, Harris J, et al. Diagnosis and Management of Vitiligo From the Perspectives of Patients and Healthcare Professionals: Findings From the Global VALIANT Study. Presented at: Maui Derm for Dermatologists, 24 January 2022, Maui, HI.

[20] Bibeau K, et al. Exploring the Natural and Treatment History of Vitiligo: Findings From the Global VALIANT Study. Presented at: Maui Derm for Dermatologists, 24 January 2022, Maui, HI.

[21] Bibeau K, Harris J, et al. Diagnosis and Management of Vitiligo From the Perspectives of Patients and Healthcare Professionals: Findings From the Global VALIANT Study. Presented at: Maui Derm for Dermatologists, 24 January 2022, Maui, HI

[22] European Academy of Dermatology and Venereology. Call to Action on Chronic Inflammatory Skin Disease. Available at: https://eadv.org/wp-content/uploads/2023/10/EADV-Call-to-Action-on-Chronic-Inflammatory-Skin-Disease_WEB.pdf (Accessed October 2024).

[23] GlobalSkin. Atopic Dermatitis: A Collective Global Voice for Improving Care. Available at: https://globalskin.org/images/Publications/AtopicDermatitis.pdf (Accessed October 2024).

Overview of the Methodology

This White Paper acknowledges the profound impact of vitiligo on people across Europe and globally. However, for the purposes of this analysis, the focus is on seven specific countries: Belgium, France, Germany, Italy, the Netherlands, Spain and the United Kingdom (UK). These countries were selected as the starting point for the investigation, enabling the development of a basic understanding and the creation of a framework for additional research.

Throughout the study, to coordinate the development of the White Paper in an efficient manner, a Steering Committee (SC) was created, bringing together two healthcare professionals and one patient representative. Moreover, to ensure comprehensive input from all relevant communities, the work of the SC was validated and supported by a Scientific Working Group (SWG), composed of healthcare professionals, and a Patient Working Group (PWG), consisting of representatives from patient organisations dedicated to vitiligo.[24,25] Both the SWG and PWG involved representatives from the selected countries (also referred as experts and expert group).

For the development of the White Paper, a mixed methodology was used to ensure a comprehensive analysis. This included a thorough literature review complemented by an online survey, semi-structured interviews, and offline iterative consultations. These diverse methods contributed to the effective alignment on priorities and formulation of well-rounded recommendations for action.

The Patient Pathway

All findings have been categorised under five overarching themes, corresponding to the different steps in the patient pathway, notably:

01/ *Awareness and pre-diagnosis;*

02/ *Diagnosis and referral;*

03/ *Treatment initiation and disease management;*

04/ *Follow-up and support;*

05/ *Policy prioritisation and reimbursement coverage.*

For each step, we have identified challenges and potential solutions listed below as policy recommendations. For more information about the process, please refer to the detailed methodology in Annex.

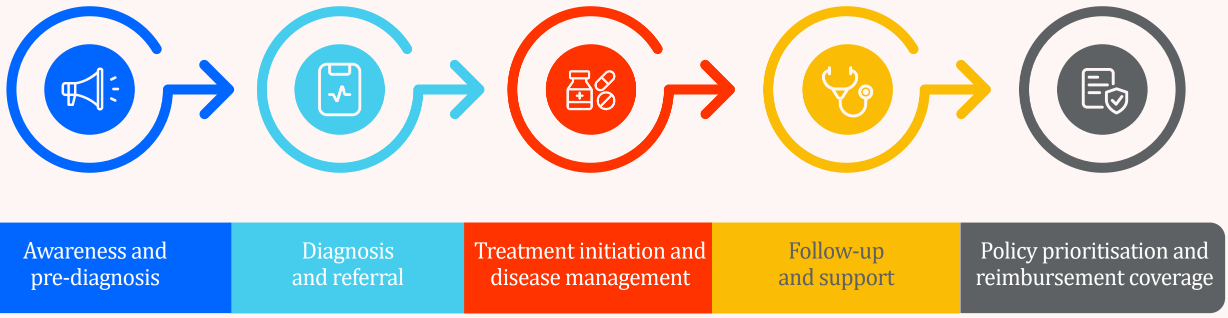

Fig. 1 The vitiligo care pathway steps

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[24] The full list of SWG members can be found in the Annex of this White Paper.
[25] The full list of SWG members can be found in the Annex of this White Paper.

01

Awareness & Pre-diagnosis

STEP 1: Awareness & Pre-diagnosis

Awareness and pre-diagnosis

KEY CHALLENGES

1.1 A lack of awareness and knowledge leads to misconceptions about vitiligo

1.2 Vitiligo’s impact extends beyond the physical

1.3 Inconsistent training of General Practitioners on vitiligo remains a key issue

1.4 Clinical guidelines on vitiligo remain inconsistent across Europe

> *The realm of vitiligo is undeniably intricate, characterised by multifaceted challenges and prevailing misconceptions that demand a comprehensive approach to care.*

The first step of the vitiligo patient pathway identified by the experts involved in the development of this White Paper was awareness and pre-diagnosis.

Upon discussion, several gaps and bottlenecks became clear, including a lack of awareness of vitiligo among the public and within the medical community which leads to numerous unmet needs within the patient community.

1.1

A lack of awareness and knowledge leads to misconceptions about vitiligo

Common misconceptions about vitiligo in general were found on a global scale, including a widespread belief that it is contagious, caused by external forces, such as witchcraft or evil spirits, or that vitiligo is associated with a lack of hygiene or an infection.[26, 27]

A correlation between knowledge of vitiligo and attitudes towards individuals with vitiligo was also found, broadly showing that those well-informed about the disease usually exhibit fewer negative attitudes and more positive ones.[28]

Awareness initiatives, including public or hospital-based vitiligo campaigns on the signs and symptoms of vitiligo, were found to be lacking across countries aside from Italy and the Netherlands, leaving many without basic information about vitiligo.

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[26] Ezzedine K, Eleftheriadou K, Jones H, et al. Psychosocial Effects of Vitiligo: A Systematic Literature Review. *J Am Acad Dermatol.* 2021; 22(6):757-774.

[27] Millington GWM, Levell NJ. Vitiligo: the historical curse of depigmentation. *Int J Dermatol.* 2007;46(9):990-5.

[28] Ezzedine K, Eleftheriadou V, Jones H, et al. Psychosocial Effects of Vitiligo: A Systematic Literature Review. *Am J Clin Dermatol.* 2021;22(6):757-774.

1.2

Vitiligo's impact extends beyond the physical

The psychological distress and feelings of social isolation driven by stigma are among the most prevalent psychosocial comorbidities for those living with vitiligo, along with adjustment disorders, sleep disturbances, relationship difficulties and avoidance or withdrawn behaviour.[29]

→ **25-50%**

Approximately 25% to 50% of patients surveyed in Europe reported that vitiligo impacted their quality of life and emotional well-being, including self-esteem and feelings of stigmatization, as well as their relationships and careers.[30]

→ **42.0%**

of European participants in a global survey reported that vitiligo lowered their confidence and increased self-consciousness, with notably higher percentages in the UK (54.2%) and France (45.6%) compared with Spain (33.0%) and Italy (31.0%).[31]

→ **53.9%**

of people living with vitiligo said they often conceal their condition, most notably in Germany (60.4%) and France (58.4%).[32]

Providing psychotherapy and/or counselling for individuals living with vitiligo is important to address the impact of stigmatisation, but educating the general public about the disease could help to reduce the stigma surrounding the condition for their benefit as well as the benefit of their caregivers.[33]

> *"Personally, I don't feel stigma, but I do avoid certain situations because of vitiligo. It's more about other people staring in the gym changing room or in a disco"*
>
> *— Spanish patient*

> *"Stigma varies from person to person and how the lesions appear – if they are on the face or on other body parts. It also depends on if people realise that someone has vitiligo"*
>
> *— Spanish healthcare professional*

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[29] Ezzedine K, Eleftheriadou V, Jones H, et al. Psychosocial Effects of Vitiligo: A Systematic Literature Review. *Am J Clin Dermatol.* 2021;22(6):757-774.

[30] Ezzedine K, Harris JE, Hamzavi IH, et al. Mental Health and Psychosocial Burden Among Patients Living With Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1384.

[31] Ezzedine K, Harris JE, Hamzavi IH, et al. Mental Health and Psychosocial Burden Among Patients Living With Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1384.

[32] Ezzedine K, Harris JE, Hamzavi IH, et al. Mental Health and Psychosocial Burden Among Patients Living With Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1384.

[33] Ezzedine K, Eleftheriadou V, Jones H, et al. Psychosocial Effects of Vitiligo: A Systematic Literature Review. *Am J Clin Dermatol.* 2021;22(6):757-774.

- 🟤 Always
- 🟠 Often
- 🟡 Occasionally
- 🟢 Rarely
- ○ N/A

GROUPS OF PATIENTS EXPERIENCING STIGMATISATION OF VITILIGO		COUNTRIES						
		Belgium	France	Germany	Italy	Netherlands	Spain	UK
ENVIRONMENT	**Patients with vitiligo**	🟠	🟠	🟡	🟠	🟡	🟡	🟠
	In professional environments	🟡	🟠	🟡	🟠	🟠	🟡	🟠
	In non-professional environments	🟠	🟠	🟠	🟠	🟠	🟡	🟠
	In public spaces	○	🟠	🟠	🟠	🟠	🟡	🟠
	In a family environment	○	🟡	🟡	🟡	🟡	🟡	🟠
AGE	Small children / pupils	🟠	🟠	🟠	🟠	🟤	🟡	🟡
	Young people / Students	○	🟠	🟠	🟤	🟠	🟡	🟠
	Adults	🟠	🟠	🟡	🟠	🟠	🟡	🟠
	Seniors	○	🟡	🟢	🟢	🟡	🟢	🟡
SOCIO-CULTURAL DYNAMICS	In underprivileged socio-economic groups	🟠	🟠	🟡	🟡	🟠	🟡	🟠
	Individuals living in remote areas	○	🟡	○	🟡	🟡	🟡	🟠
	Various ethnic sub-groups	🟠	🟠	🟠	🟡	🟤	🟡	🟠

NB This table was created using responses from SWG and PWG members collected through two corresponding surveys. As per the project’s methodology, reconciliatory interviews were conducted to align divergent responses. Where answers differed and were not reconciled in an interview, either the most common value or the middle value was taken. In cases where the differing answers were equally divided among respondents, the higher value was taken.

1.3

Inconsistent training of General Practitioners on vitiligo remains a key issue

Although literature on GPs' knowledge of the disease is limited, many participants in one UK study believed that GPs generally lack in-depth knowledge about vitiligo and could only offer limited information and guidance to patients.[34]

Vitiligo is not consistently included on the GP curriculum, nor is treatment and care consistently taught across countries, though pathophysiological mechanisms and chronicity of vitiligo together with vitiligo treatment strategies are commonly included on the dermatology curricula across all countries.

1.4

Clinical guidelines on vitiligo remain inconsistent across Europe

At global level, the 'Worldwide expert recommendations for the diagnosis and management of vitiligo' provide guidance on how to diagnose and treat the condition, but this is currently only promoted by national dermatological societies in Belgium and the UK.

At a local level, a treatment algorithm was developed by the European Dermatological Forum[35] in 2013. However, therapeutic recommendations vary according to EU countries.

Vitiligo included in GPs' curriculum	
Belgium	N/A
France	No
Germany	No
Italy	Yes
Netherlands	No
Spain	No
UK	Yes

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[34] Teasdale E, Muller I, Abdullah Sani A et al. Views and experiences of seeking information and help for vitiligo: a qualitative study of written accounts. *BMJ Open.* 2018;8(1):e018652.

[35] Taieb A, Alomar A, et al. Guidelines for the Management of Vitiligo: The European Dermatology Forum Consensus. *Br J Dermatol.* 2013;168(1):5-19.

> *"The new international recommendations are rather unknown to dermatologists in Netherlands. However, there are national guidelines, as well as a summary, that are rather well-known. However, not all dermatologists are so well aware that the guidelines exist. It also depends on the specialisation of the dermatologist"*
>
> *— Dutch healthcare professional*

02

Diagnosis & referral

STEP 2: Diagnosis & referral

Diagnosis & referral

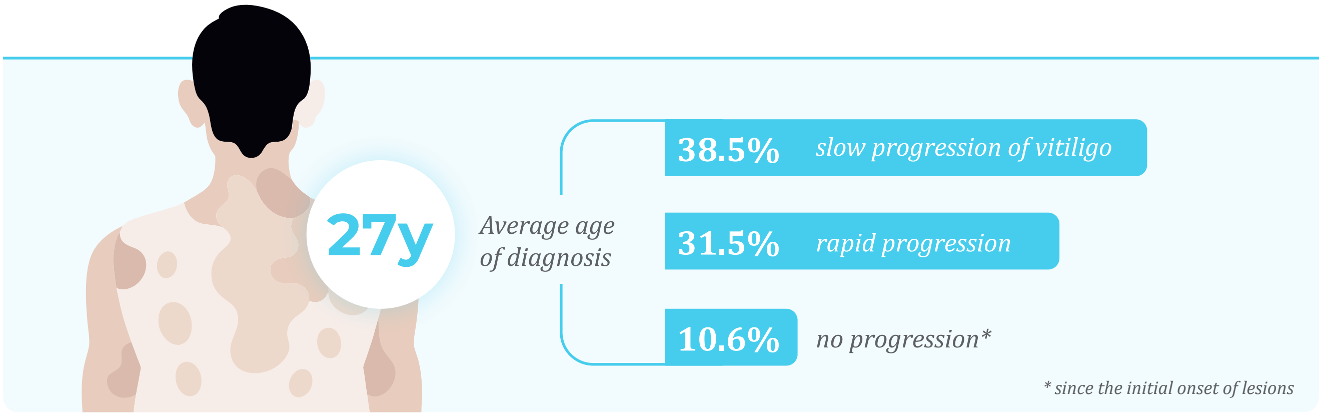
KEY CHALLENGES

2.1	Patients face a prolonged and complex journey to diagnosis
2.2	Diagnosis time varies by years, not months
2.3	Misdiagnosis remains a prevalent issue in Vitiligo cases
2.4	People seek information upon diagnosis, but it remains elusive in many countries
2.5	Issues in accessing specialists are driven by more than time constraints

> *From unpredictable disease progression and variability in appearance to a lack of knowledge at primary care level, the journey to a formal vitiligo diagnosis can be difficult.*

According to European research, the disease onset commonly occurs by 30 years of age. The same study confirmed that **most patients experienced either slow (38.5%) or rapid (31.5%) progression of vitiligo**, while 10.6%, reported no progression of the condition since the initial onset of lesions.[36]

Roughly half of the patients participating in the study (50.3%) reported a family history of vitiligo, with the highest prevalence noted in individuals from France (66.4%) and Germany (58.8%).[37]



** since the initial onset of lesions*

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36 van Geel N, Harris JE, Hamzavi IH, et al. Exploring the Natural and Treatment History of Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1401.

37 van Geel N, Harris JE, Hamzavi IH, et al. Exploring the Natural and Treatment History of Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1401.

2.1

Patients face a prolonged and complex journey to diagnosis

While the condition is usually diagnosed by a physical examination supported by a Wood's lamp examination, additional tests such as a skin biopsy, mycological examination, and specific blood tests may be necessary to rule out conditions like fungal infections, cutaneous lymphoma, and other disorders.[38]

As it stands, guidance for HCPs to diagnose vitiligo is specified by national guidelines in Germany, Italy, Netherlands and the UK, in specialised centres in France and Spain, and not at all in Belgium.

In addition to this, Germany was the only country found to have protocols for assessing disease progression or disease activity. HCPs, and particularly dermatologists, look for hypochromic borders* (using a Wood's lamp) to monitor the activity of vitiligo, followed by looking for confetti-like depigmentation and Koebner phenomenon.

* Hypochromic areas/borders are vitiligo lesions with ill-defined borders and/or lighter in colour areas.

> *"Unfortunately, some dermatologists in France are not monitoring the activity of vitiligo, some do not even have a Wood's lamp. Usually, in expert centres, they are assessing activity and further refer patients where necessary"*
>
> *— French healthcare professional*

With patients in Belgium, Spain and the UK reportedly unaware of diagnostic procedures, HCPs' knowledge and application of the internationally recommended procedures, as well as the existence of protocols, is particularly important. Awareness is only slightly higher in France, Germany, Italy and the Netherlands, where patients are sometimes familiar with these processes.

2.2

Diagnosis time varies by years, not months

2.5 years

In Europe, there is on average a **2.5-year gap** between patients first noticing lesions and receiving an official diagnosis.[39]

However, the healthcare professionals and patient experts in the working groups indicated that in most countries (Belgium, France, Italy, Netherlands, Spain and UK) it takes between 6 months and 1 year to get a first diagnosis. The exception is Germany, where it was reported to take between 1 and 3 months.

The time it takes to get a vitiligo diagnosis is affected by the amount of time that the healthcare professional can spend with each patient seeking one, evidenced by the significant differences between hospital-based and private practice reported in Italy, Spain, the UK and Germany.

2.3

Misdiagnosis remains a prevalent issue in Vitiligo cases

The inconsistent progression of lesions in vitiligo can often result in misdiagnosis of other disorders that cause hypo- or depigmentation.[40]

Such misidentification can prevent patients from receiving early interventions key to manage the progression of depigmentation, and (potentially) stabilise the condition.

In Europe, roughly **3 in 7 individuals** with vitiligo have previously received an incorrect diagnosis.[41]

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[38] van Geel N, Reinhart S, Taïeb A, et al. Worldwide expert recommendations for the diagnosis and management of vitiligo: Position statement from the International Vitiligo Task Force Part 1: towards a new management algorithm. *J Eur Acad Dermatol Venereol.* 2023;37(11):2173-2184.

[39] van Geel N, Harris JE, Hamzavi IH, et al. Exploring the Natural and Treatment History of Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1401.

[40] van Geel N, Reinhart S, Taïeb A, et al. Worldwide expert recommendations for the diagnosis and management of vitiligo: Position statement from the International Vitiligo Task Force Part 1: towards a new management algorithm. *J Eur Acad Dermatol Venereol.* 2023;37(11):2173-2184.

[41] Bibeau K, Harris J, et al. Diagnosis and Management of Vitiligo From the Perspectives of Patients and Healthcare Professionals: Findings From the Global VALIANT Study. Presented at: Maui Derm for Dermatologists, 24 January 2022, Maui, HI.

At global level, misdiagnosis rates were higher in:

64.4%

People with
darker skin

61.5%

People with **more than 5%** of
their body surface area affected

54.3%

People with
lesions on their face

44%

Male (45.5%) and female (44.0%) patients reported similar frequencies of being misdiagnosed.[42]

45.5%

The same global study confirmed that:

62.3%

of people living with vitiligo were first diagnosed with the condition by a dermatology-focused HCP

35.6%

were diagnosed by family or primary care doctors, nurse practitioners or physicians’ assistants

2.1%

were diagnosed by other types of healthcare providers

66.6% vs 40.5%

People living with vitiligo who were treated by a primary care physician had a higher chance of being misdiagnosed (66.6%), than those who were treated by a dermatologist (40.5%)[43]

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[42] Hamzavi IH, Bibeau K, Grimes P, et al. Exploring the natural and treatment history of vitiligo: perceptions of patients and healthcare professionals from the global VALIANT study. *Br J Dermatol.* 2023;189(5):569-577.

[43] Hamzavi IH, Bibeau K, Grimes P, et al. Exploring the natural and treatment history of vitiligo: perceptions of patients and healthcare professionals from the global VALIANT study. *Br J Dermatol.* 2023;189(5):569-577.

> *“Most dermatologists, both private and hospital-based, can usually diagnose vitiligo easily. The main problems are access to dermatologists, and the misdiagnoses made by general practitioners and other HCPs”*
>
> *— French healthcare professional*

Higher rates of misdiagnoses, especially among primary care providers, can be linked to a lack of knowledge on chronicity and progression of vitiligo. For example, participants in a UK study commonly believed that GPs generally lack in-depth knowledge about vitiligo, resulting in them only being able to offer patients limited information and guidance.[44]

2.4
People seek information upon diagnosis, but it remains elusive in many countries

Not receiving comprehensive information about the disease at the time of diagnosis is perceived by patients as a significant factor affecting their experience, with “providing information and reassurance about the nature of the disease” considered the top priority by Dutch dermatologists (68%).[45, 46]

> *“In the Netherlands, some resources exist, and experts usually flag the* ***Vitiligo.nl*** *website, but other dermatologists typically are not doing this except if they have a special interest in vitiligo”*
>
> *— Dutch healthcare professional*

Availability of patient information resources at the time of diagnosis

Belgium	Rarely
France	Rarely
Germany	Generally
Italy	Rarely
Netherlands	Sometimes
Spain	Sometimes
UK	Sometimes

Except for France, any of the examined countries had in place trainings to effectively communicate a vitiligo diagnosis, which aggravates the major concern among people living with vitiligo concerning the minimisation of the disease and its impact when receiving a diagnosis. One study in Spain confirmed that patients perceive a tendency to downplay the disease among HCPs, who often view it as merely a cosmetic issue. Ultimately, patients often changed doctors, driven by low trust in their healthcare provider, perceived lack of empathy and minimisation of vitiligo to a cosmetic concern. [47]

2.5
Issues in accessing specialists are driven by more than time constraints

While literature on challenges in accessing vitiligo expertise is scarce, data from Spain does indicate that the difficulty of access to a specialist is perceived by most patients as a key barrier.

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[44] Teasdale E, Muller I, Abdullah Sani A, et al. Views and experiences of seeking information and help for vitiligo: a qualitative study of written accounts. *BMJ Open.* 2018;8(1):e018652.

[45] (Presentation) “Invitsibles - dando voz al vitiligo – Making the disease visible and advancing its management”, IESE Center for Research in Healthcare Innovation Management + INCYTE + Outcomes10

[46] Njoo MD, Bossuyt PM, Westerhof W. Management of vitiligo. Results of a questionnaire among dermatologists in The Netherlands. *Int J Dermatol.* 1999;38(11):866-72.

[47] (Presentation) “Invitsibles - dando voz al vitiligo – Making the disease visible and advancing its management”, IESE Center for Research in Healthcare Innovation Management + INCYTE + Outcomes10

When asked about the main bottlenecks in accessing dermatologists or vitiligo specialists, the members of the Scientific and Patient Working Groups indicated that the top five challenges are:

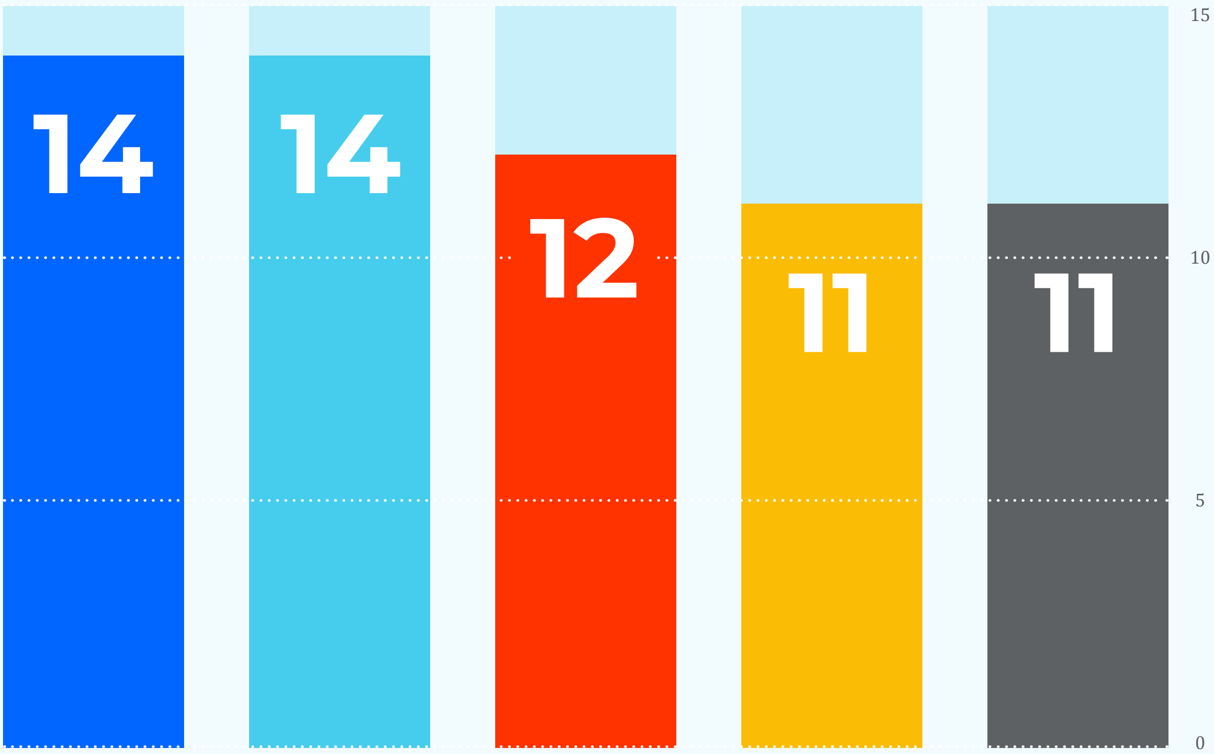
● ***GPs' belief that there are no treatments for vitiligo***

● ***Lack of understanding of vitiligo's impact***

● ***A 'wait and watch' attitude from GPs***

● ***Insufficient number of specialist dermatologists***

● ***Long waiting lists***



The chart shows responses from 15 participants identifying barriers to accessing dermatologists or vitiligo specialists. Each bar represents how often a specific bottleneck was selected in a multiple-choice question.

03

Disease management (I) – Treatment initiation

STEP 3: Disease management (I) – Treatment initiation

Disease management (I) – Treatment initiation

KEY CHALLENGES

3.1 Vitiligo treatment remains a long road of trial and error

3.2 Patients are left without information on their treatment options

3.3 Comorbidities management advice is often rare or non-existent

3.4 Shared decision-making tools are not consistently applied

Having access to treatment means having the ability to utilise "safe, quality and appropriate services, treatments, preventive care and health promotion activities".[48]

Access is a principal objective within the Sustainable Development Goals (SDGs) set for 2030. Specifically, Goal 3 highlights the importance of attaining access to "quality essential health-care services" and ensuring "access to safe, effective, quality and affordable essential medicines and vaccines for all" as a crucial step toward achieving universal health coverage (UHC).[49]

The reform of the EU pharmaceutical legislation is one such way that the EU is seeking to achieve the SDG, working to ensure that all EU patients receive timely and equitable access to safe, effective and affordable medications, and improve the security of supply to guarantee that medicines are accessible to patients no matter where they reside in the EU.[50]

Due to the complex nature of vitiligo the treatment selected will depend on the patient's age, extent and location of skin involvement, as well as the rate at which the disease is progressing, and its impact on their daily life.

For active vitiligo, treatments include topical ointment creams, phototherapy, and systemic treatment for rapidly progressing cases.

For stable vitiligo, maintenance treatment is advised to prevent relapses, and topical treatment with or without phototherapy for repigmentation. Surgical options are considered for localised vitiligo that has remained stable for at least 12 months without any treatment.[51]

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[48] International Alliance of Patients' Organizations. Access to treatment. Available at: https://www.iapo.org.uk/access-treatment (Accessed October 2024).

[49] United Nations. Ensure healthy lives and promote well-being for all at all ages. Available at: https://sdgs.un.org/goals/goal3 (Accessed October 2024).

[50] European Commission. Reform of the EU pharmaceutical legislation. Available at: https://health.ec.europa.eu/medicinal-products/pharmaceutical-strategy-europe/reform-eu-pharmaceutical-legislation_en (Accessed October 2024).

[51] van Geel N, Reinhart S, Taïeb A, et al. Worldwide expert recommendations for the diagnosis and management of vitiligo: Position statement from the International Vitiligo Task Force Part 1: towards a new management algorithm. *J Eur Acad Dermatol Venereol.* 2023;37(11):2173-2184.

3.1

Vitiligo treatment remains a long road of trial and error

The decision of which treatment is appropriate for vitiligo is more complicated than it may seem, posing a significant challenge for healthcare professionals and the people living with the condition.

Complex and highly individualised, the choice is influenced by a multitude of factors such as the subtype of the disease, the extent and distribution of affected areas and the activity of the disease.[52] In vitiligo, **early treatment is particularly important given that interventions are more effective at slowing or stopping the progression of pigment loss in the initial stages of the disease.**

Patients already face a long pathway of trial and error with various therapies, and no single approach guarantees success. This uncertainty can lead to frustration and a significant emotional burden as patients navigate their treatment options, seeking both medical and psychological relief.

Due to the complex nature of vitiligo treatment, the lines between pharmacological and non-pharmacological methods are often blurred. Achieving optimal repigmentation usually takes between 6 to 24 months, requiring a combination of both approaches to be effective. It is essential that both patients and healthcare providers are aware of this timeline. Treatments for vitiligo frequently involve integrating these methods, making it challenging to distinguish and evaluate them separately in studies.

Due to the complex nature of vitiligo treatment, the lines between pharmacological and non-pharmacological methods are often blurred. Treatments for vitiligo frequently involve a combination of both approaches, making it challenging to distinguish and evaluate them separately in studies.

This is likely due to vitiligo having been considered a cosmetic issue by both HCPs and payers for a long time. In Belgium, nearly all dermatologists report that they frequently inform their patients about their condition, but only 36% encourage treatment, mainly because of pessimism about the expected treatment results.[53] In France, 83.8% of people living with vitiligo were not prescribed any treatment, while in the UK, 85% did not receive any treatment in 2019.[54, 55]

65%

of people diagnosed with vitiligo in Europe have been told that their condition cannot be treated.

Of this 65%, 37% did not know of any available treatments or did not seek vitiligo treatment again.[56] A higher proportion of people treated by primary care HCPs (68.8%) were informed that their vitiligo was untreatable compared to patients under the care of dermatologists.[57]

In some countries, including Belgium and Germany, dermatologists tend to prioritise consultations with patients with other skin diseases (e.g. psoriasis or atopic dermatitis) over consultations with vitiligo patients. This occurs less frequently in France, Italy, Netherlands and UK and Spain.

Although there is no data available, experts have highlighted that this is mainly because HCPs are not very familiar with vitiligo, approaching it as a cosmetic disease with no effective treatment.

> *“Vitiligo is still regarded as a cosmetic disease because until now, treatments have been only partially successful and do not have the same quick results like in other conditions”*
>
> *— Dutch healthcare professional*

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[52] Bergqvist C, Ezzedine K. Vitiligo: A Focus on Pathogenesis and its Therapeutic Implications. *J Dermatol.* 2021;48(3):252-270.

[53] Ongenae K, Van Geel N, De Schepper S, et al. Management of vitiligo patients and attitude of dermatologists towards vitiligo. *Eur J Dermatol.* 2004;14(3):177-81.

[54] Ezzedine K, Seneschal J, Da Silva A, et al. Vitiligo patient population and disease burden in France: VIOLIN study results from the CONSTANCES cohort. *J Eur Acad Dermatol Venereol.* 2023;37(11):2249-2258.

[55] Eleftheriadou V, Delattre C, Chetty-Mhlanga S, et al. Burden of disease and treatment patterns in patients with vitiligo: findings from a national longitudinal retrospective study in the UK. *Br J Dermatol.* 2024;191(2):216-224.

[56] Bibeau K, Harris J, et al. Diagnosis and Management of Vitiligo From the Perspectives of Patients and Healthcare Professionals: Findings From the Global VALIANT Study. Presented at: Maui Derm for Dermatologists, 24 January 2022, Maui, H

[57] Hamzavi IH, Bibeau K, Grimes P, et al. Exploring the natural and treatment history of vitiligo: perceptions of patients and healthcare professionals from the global VALIANT study. *Br J Dermatol.* 2023;189(5):569-577.

Providing patients with information about vitiligo treatment is crucial to support informed treatment decision-making, improve treatment adherence and set realistic expectations.

Availability of information for patients about treatments, as provided by HCPs	
Belgium	None
France	None
Germany	In limited setting
Italy	In limited setting
Netherlands	None
Spain	None
UK	None

3.2

Patients are left without information on their treatment options

Although many vitiligo patients in Europe are not prescribed any treatment, one study confirmed that patients who did try treatment have used approximately 5 different management strategies since diagnosis. A larger number of treatments were used by patients from Germany (6.5) in comparison with those from the UK (4.9), Italy (4.7), France (4.6) and Spain (4.1), Despite this, 51.6% of European patients found continuing treatment with no guarantee of success frustrating.[58, 59] Nearly two thirds of patients were hopeful for new treatments in the EU.[60] Patient advocacy groups highlight concerns that individuals without access to prescription treatments may seek alternative therapies, some of which may not meet established safety standards.

It is worth noting that treatment goals differ among patients and HCPs.

- For patients, they seek to reduce or stop the spread of symptoms or repigment affected skin, with no clear expectation on which is priority. Additionally, many are unclear on what to expect, so have no treatment goals
- For HCPs, there is a common understanding of the need for a step by step approach to treatment. This starts with improving long-term clinical outcomes, then repigmentation of affected skin, before ultimately working to stop the spread of symptoms.n[61]

Stakeholders involved in the development of the White Paper highlighted the importance of patients being well informed about the treatment and its duration, the nature of the condition and the key role of adherence in treatment success. While the literature on treatment adherence in Europe is limited, one global study found that patient-reported treatment compliance was higher (75%) than HCP-reported estimations (51.8%).[62]

Communication of the importance of long-term treatment adherence in patient-doctor consultations	
Belgium	None
France	Rarely
Germany	Sometimes
Italy	Always
Netherlands	Sometimes
Spain	Rarely
UK	Rarely

> *"In general, vitiligo patients, as all patients want to have fast therapeutic results as in other skin diseases, such as psoriasis or atopic dermatitis. Nevertheless, it takes time to explain to them the nature of this complex disease"*
>
> *— German healthcare professional*

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[58] Ezzedine K, Harris JE, Bibeau K, et al. Treatment Burden Among Patients With Vitiligo: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1402.

[59] van Geel N, Harris JE, Hamzavi IH, et al. Exploring the Natural and Treatment History of Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1401

[60] Bibeau K, et al. Exploring the Natural and Treatment History of Vitiligo: Findings from the Global VALIANT Study. Presented at: Maui Derm for Dermatologists, 24 January 2022, Maui, HI.

[61] Hamzavi IH, Bibeau K, Grimes P, et al. Exploring the natural and treatment history of vitiligo: perceptions of patients and healthcare professionals from the global VALIANT study. *Br J Dermatol.* 2023;189(5):569-577.

[62] Hamzavi IH, Bibeau K, Grimes P, et al. Exploring the natural and treatment history of vitiligo: perceptions of patients and healthcare professionals from the global VALIANT study. *Br J Dermatol.* 2023;189(5):569-577.

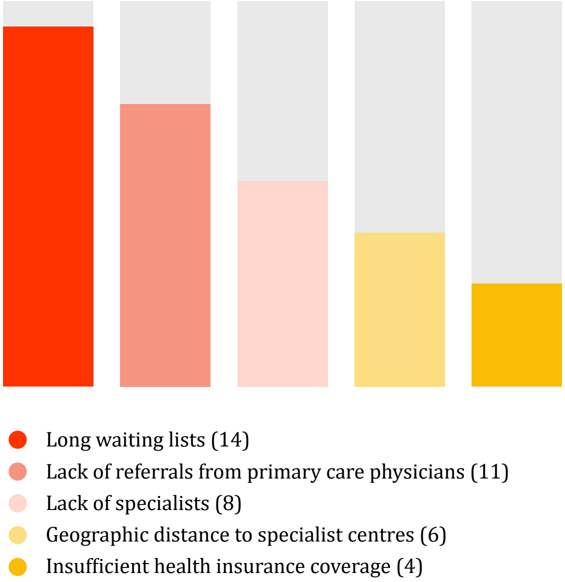
3.3
Comorbidities management advice is often rare or non-existent

Vitiligo is linked to a higher occurrence of associated health conditions, with the most frequent being thyroid disease, as well as psoriasis, type 1 diabetes mellitus, rheumatoid arthritis and alopecia areata amongst others. [63]

The survey shared with the SWG and PWG members confirmed that the most screened comorbidity is thyroid disease. Diabetes and alopecia areata are sometimes screened in Germany, Spain and the UK. Screening for psychological conditions is common only in Spain.

It also revealed that patients face several bottlenecks in access to other specialists, with long waiting lists being the main one (14 answers), followed by the lack of referrals from primary care physicians (11), a lack of specialists (8), geographic distance to specialist centres (6) and insufficient health insurance coverage (4).

Care access bottlenecks



Furthermore, academic literature in Europe is limited in relation to the involvement of multidisciplinary teams in the management of patients with comorbidities. The survey completed by SWG and PWG members indicates that patients with comorbidities in France, Germany, the Netherlands and the UK rarely have access to multi-disciplinary teams.

Access to multi-disciplinary teams by patients with comorbidities

Belgium	None
France	Rarely
Germany	Rarely
Italy	None
Netherlands	Rarely
Spain	None
UK	Rarely

3.4
Shared decision-making tools are not consistently applied

The ‘Worldwide expert recommendations for the diagnosis and management of vitiligo’ highlight the importance of shared decision-making to inform patients about the available treatment options, ask about their preferences, address expectations and explain the pros, cons and risks associated with each therapeutic option.[64]

However, the shared decision-making process is often inadequate. From the patient’s perspective, there exists a notable deficiency in understanding both vitiligo and its available treatments. Conversely, healthcare professionals often lack a full appreciation of the psychosocial impact and the overall burden the disease places on patients.

While a shared decision-making tool has recently been developed and validated for use in specialised consultation for vitiligo, the tool is not yet widely used, and communication between HCPs and patients is sometimes limited.[65] For example, in Belgium, one study found that 50% of vitiligo patients were not adequately informed about their disease and its treatment during their first doctor visit.[66] Similarly, a lack of information and empathy was noted in Spain and the UK, which sometimes pushed patients to abandon treatment, turn to

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[63] Dahir AM, Thomsen SF. Comorbidities in vitiligo: comprehensive review. *Int J Dermatol.* 2018;57(10):1157-1164.

[64] van Geel N, Reinhart S, Taïeb A, et al. Worldwide expert recommendations for the diagnosis and management of vitiligo: Position statement from the International Vitiligo Task Force Part 1: towards a new management algorithm. *J Eur Acad Dermatol Venereol.* 2023;37(11):2173-2184.

[65] Shourick J, Ahmed M, Seneschal J, et al. Development of a shared decision-making tool in vitiligo: an international study. *Br J Dermatol.* 2021;185(4):787-796.

[66] Ongenae K, Van Geel N, De Schepper S, et al. Management of vitiligo patients and attitude of dermatologists towards vitiligo. *Eur J Dermatol.* 2004;14(3):177-81.

pseudo-treatments or seek information from other, mainly online, sources.[67, 68]

The survey undertaken for the development of this White Paper confirmed that shared decision-making tools are used only in a minority of the countries (Germany, Italy, and the UK) and even then, only used in certain settings.

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67 (Presentation) "Invitsibles - dando voz al vitiligo – Making the disease visible and advancing its management", IESE Center for Research in Healthcare Innovation Management + INCYTE + Outcomes10

68 Teasdale E, Muller I, Abdullah Sani A, et al. Views and experiences of seeking information and help for vitiligo: a qualitative study of written accounts. *BMJ Open.* 2018;8(1):e018652.

04

Disease management (II) - Follow-up & support

STEP 4: Disease management (II) - Follow-up & support

Disease management (II) - Follow-up & support

KEY CHALLENGES

4.1 Treatment follow-up consultations are too often not part of routine care

4.2 The mental health impact of vitiligo is pressing, yet under treated

4.3 Patients rarely have access to information on clinical trials

4.4 No international registry for patients with vitiligo exists

4.5 No consensus on how best to measure vitiligo activity

Given that vitiligo is a complex autoimmune disease, regular follow-up is essential for treatment success.

The International Vitiligo Task Force highlights that assessing disease activity is key to personalised vitiligo treatment, including evaluating previous therapy and patient compliance. Moreover, it recommends reassessing the treatment every 3 to 6 months using serial photography to monitor progress. [69]

At the same time, follow-up is not only important for monitoring disease activity, but also to make sure that patients and caretakers understand the information received at diagnosis or during their first visit, and to clarify any potential remaining questions.[70] Despite this, 42% of people who receive a vitiligo diagnosis in Europe report that they found it difficult to get a follow-up appointment.[71]

4.1

Treatment follow-up consultations are too often not part of routine care

The literature surrounding follow-up strategies for people living with vitiligo is sparse, with focus being on initial treatment efficacy and short-term outcomes, except one project in Spain noting an absence of multidisciplinary approaches (like active follow-up and screening for comorbidities).[72] According to the survey results, the established protocols for follow-up after treatment vary by country and extent of skin involvement, from surgical therapy for unresponsive vitiligo to maintenance treatment with 0.1% tacrolimus ointment.[73]

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[69] van Geel N, Reinhart S, Taïeb A, et al. Worldwide expert recommendations for the diagnosis and management of vitiligo: Position statement from the International Vitiligo Task Force Part 1: towards a new management algorithm. *J Eur Acad Dermatol Venereol.* 2023;37(11):2173-2184.

[70] van Geel N, Reinhart S, Taïeb A, et al. Worldwide expert recommendations for the diagnosis and management of vitiligo: Position statement from the International Vitiligo Task Force Part 1: towards a new management algorithm. *J Eur Acad Dermatol Venereol.* 2023;37(11):2173-2184.

[71] Ezzedine K, Harris JE, Bibeau K, et al. Treatment Burden Among Patients With Vitiligo: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1402.

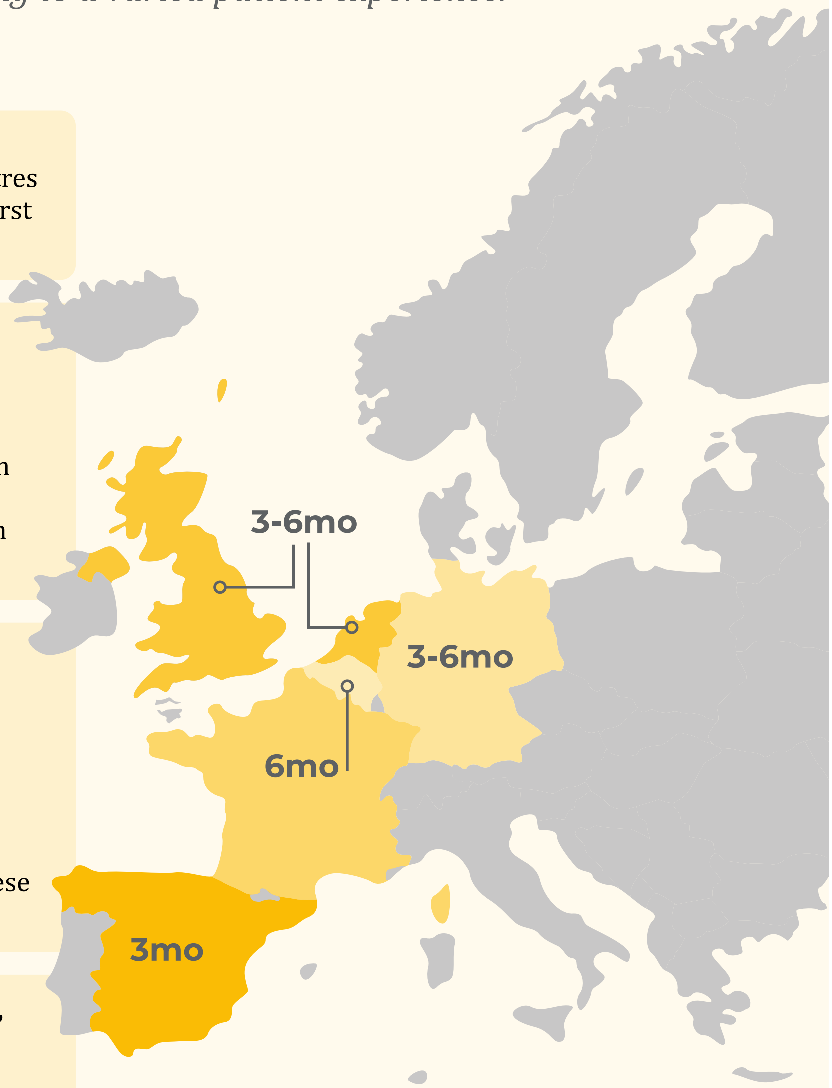
[72] (Presentation) "Invitsibles - dando voz al vitiligo – Making the disease visible and advancing its management", IESE Center for Research in Healthcare Innovation Management + INCYTE + Outcomes10

[73] Eleftheriadou V, Atkar R, Batchelor J, et al. British Association of Dermatologists guidelines for the management of people with vitiligo 2021. *Br J Dermatol.* 2021;186(1):18-29.

> *"In France, follow-up exists only when dermatologists prescribe treatment. However, one must not forget that in our country, 83% of vitiligo patients report not having received any prescribed treatment for their disease!"*
>
> *— French healthcare professional*

> *"Waiting lists are a key issue that impact scheduling review visits"*
>
> *— Spanish healthcare professional*

Follow-up processes and the frequency of visits differ significantly among the studied countries, leading to a varied patient experience.



In Belgium, patients typically undergo follow-up at expert centres every six months following the first two visits.

In France, similar six-month intervals are common for follow-ups, particularly when dermatologists prescribe treatments, though patients often receive inadequate explanations about the follow-up process from healthcare professionals.

In Germany, the frequency and approach to follow-ups varies, with expert centres generally offering services every three to six months. However, despite HCPs' efforts to refer patients to private dermatologists, lengthy waiting lists often complicate these referrals.

In the Netherlands and the UK, the frequency of follow-up visits ranges from every three to every six months.

In Spain, follow-up visits depend on several factors, such as the severity of vitiligo, existing waiting lists or the type of treatment the patient is undergoing. For example, patients undergoing UVB narrowband treatment usually only attend a follow-up after three months. Similarly, if the patient collects the medication from the hospital, they will also attend a follow-up visit as medication cannot be dispensed for more than three months.

4.2

The mental health impact of vitiligo is pressing, yet under treated

In Europe, half of people living with vitiligo (49.6%) have symptoms of moderate-to-severe depression, according to the Patient Health Questionnaire-9 screener. Other mental health comorbidities that have been reported are anxiety (26.5%) and depression (23.4%).[74] This is consistent with a UK study, which found that the most common mental health disorders among patients with vitiligo were anxiety and/or depression (24.6%), depression (18.5%), anxiety (16.0%), and sleep disturbance (12.7%). Moreover, 26.6% of UK patients had a record of antidepressant/anxiolytic treatment during the 5 years after vitiligo diagnosis.[75]

At European level, treatment burden seems to be significantly greater among females, people living with vitiligo who have darker skin and those with facial lesions. Moreover, individuals with vitiligo in France and Germany are more often impacted from a quality of life and psychosocial health perspective than patients in Italy, Spain, and the UK.[76]

The same study found that vitiligo impacts the emotional well-being of a third of people in Europe living with the condition, including their self-esteem/stigmatisation.

Half of people living with vitiligo are worried about the progression of the disease.[77] This is confirmed by a study undertaken in Spain, which found that the condition often leads to stress and insecurity, particularly when it progresses and treatments fail to work as hoped.[78]

Vitiligo also influenced patient behaviour, as 53.9% of people reported hiding their vitiligo. The highest rates of this behaviour were noted in patients from Germany (60.4%) and France (58.4%).[79]

At the same time, the daily activities of patients were often affected by the condition, with patients considering the following activities the most stressful: clothing choices (49.5%), attending social activities, such as at the beach or pool (47.7%), parties/events (42.9%), work/school 40.4%), and exercising (40.9%).[80]

Additionally, many individuals with vitiligo hesitate to start families due to fears of passing on the condition, which reflects the deep emotional toll it takes. Caregivers also face challenges in supporting patients who endure stigma or bullying while navigating a medical system that often downplays the condition. Abrupt and poorly supported diagnoses can leave patients feeling abandoned, heightening the risk of despair and, in extreme cases, suicidal thoughts.

In this context, having access to a psychologist is essential. In Spain, the support most requested by people diagnosed with vitiligo was access to psychological consultations and instruction on self-care techniques. Moreover, most patients who visited a psychologist were very satisfied, with the exception of a handful of cases in which they felt misunderstood by the specialist.[81] In the same vein, participants in a UK study expressed an interest in receiving information and advice on handling the psychological and social effects of living with vitiligo.[82]

In practice, SWG and PWG members confirmed that access to psychological consultations is limited, and it is only in France and Germany where patients are occasionally referred to these services, and only in certain circumstances.

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[74] Ezzedine K, Harris JE, Hamzavi IH, et al. Mental Health and Psychosocial Burden Among Patients Living With Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1384.

[75] Thompson AR, Delattre C, Khan I, et al. MENTAL HEALTH BURDEN RELATED TO PATIENTS WITH VITILIGO IN THE UNITED KINGDOM. *Acta Dermato-Venereologica.* 2023;103:14.

[76] Ezzedine K, Harris JE, Hamzavi IH, et al. Mental Health and Psychosocial Burden Among Patients Living With Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1384.

[77] Ezzedine K, Harris JE, Hamzavi IH, et al. Mental Health and Psychosocial Burden Among Patients Living With Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1384.

[78] (Presentation) "Invitsibles - dando voz al vitiligo – Making the disease visible and advancing its management", IESE Center for Research in Healthcare Innovation Management + INCYTE + Outcomes10

[79] Ezzedine K, Harris JE, Hamzavi IH, et al. Mental Health and Psychosocial Burden Among Patients Living With Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1384.

[80] Ezzedine K, Harris JE, Hamzavi IH, et al. Mental Health and Psychosocial Burden Among Patients Living With Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1384.

[81] (Presentation) "Invitsibles - dando voz al vitiligo – Making the disease visible and advancing its management", IESE Center for Research in Healthcare Innovation Management + INCYTE + Outcomes10

[82] Teasdale E, Muller I, Abdullah Sani A et al. Views and experiences of seeking information and help for vitiligo: a qualitative study of written accounts. *BMJ Open.* 2018;8(1):e018652.

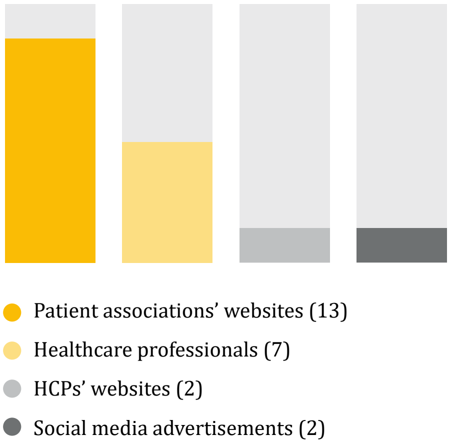
4.3

Patients rarely have access to information on clinical trials

Examination of literature (including grey literature) revealed a significant gap in the research regarding patients' access to information about clinical trials. No specific sources were identified, so this gap was addressed in the surveys to the SWG and PWG, as well as the reconciliatory interviews.

According to these, patients in Belgium, France, the Netherlands and the UK rarely have access to information about clinical trials or study opportunities in vitiligo, where patients in Germany and Italy sometimes do. Participants indicated that patients mainly get this information from patient associations' websites (13 answers), followed by healthcare professionals (7 answers), HCPs' websites (2 answers) and social media advertisements (2 answers).

Patient information sources



4.4

No international registry for patients with vitiligo exists

Although disease registries are crucial for research, and improving treatment and care, as well as for making informed policy decisions, no international registry for patients with vitiligo exists.[83]

Only **Germany and Belgium** have a patient registry for vitiligo collecting epidemiological data, patient reported outcomes and treatment-focused information - at a national and local level respectively.

In the UK, the British Association of Dermatologists recommended the development of a national registry for people living with vitiligo and undergoing systemic or light therapy, to identify outcomes and assess their safety.[84] Therefore, a pilot multi-centre registry is being developed in the UK, which will be coordinated with similar pilot multi-centre registries **in France** and the USA. Although each registry will be developed independently and there will be no sharing of data between them, coordination will occur among the chief investigators in relation to the outcomes collected.[85]

In the Netherlands, Spain and Italy, there is currently no established disease registry for vitiligo. Nevertheless, the Vitiligo Task Force of the Italian Society of Dermatology and Sexually Transmitted Diseases has recognised this gap and set the creation of a vitiligo registry as one of its key objectives.[86]

Existence of disease registries

Belgium	Local
France	Pilot registry in place
Germany	National
Italy	None
Netherlands	None
Spain	None
UK	Pilot registry in place

4.5

No consensus on how best to measure vitiligo activity

In clinical practice, managing vitiligo is complex and primarily depends on the extent and activity of the disease. Ideally, this assessment should utilise validated instruments.[87]

While there are fourteen clinician-reported outcome measures for the assessment of vitiligo

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[83] Eleftheriadou V, Hamzavi I, Min Bae J, et al. Roadmap to VIRTUAL-GLOBAL: coordinating VItiligo RegisTries for adUlts And chiLdren internationally. *Br J Dermatol.* 2023;190(1):114-116.

[84] Eleftheriadou V, Atkar R, Batchelor J, et al. British Association of Dermatologists guidelines for the management of people with vitiligo 2021. *Br J Dermatol.* 2021;186(1):18-29.

[85] CTV. Vitiligo Registry for Adults and Children in the UK. Available at: https://ctv.veeva.com/study/vitiligo-registry-for-adults-and-children-in-the-uk (Accessed October 2024).

[86] Società Italiana di Dermatologia. La diagnosi precoce per la vitiligine. Arriva la task force dei dermatologi SIDeMaST (press release). Available at: https://www.sidemast.org/blog/la-diagnosi-precoce-per-la-vitiligine-arriva-la-task-force-dei-dermatologi-sidemast (Accessed October 2024).

[87] van Geel N, Depaepe L, Vandaele V, et al. Assessing the dynamic changes in vitiligo: reliability and validity of the Vitiligo Disease Activity Score (VDAS) and Vitiligo Disease Improvement Score (VDIS). *J Eur Acad Dermatol Venereol.* 2022;36(8):1334-1341.

> *“Measurement instruments are important, but one should take into consideration that measuring success of treatment is not the same for healthcare professionals and patients. There can be differences in assessing the success of repigmentation”*
>
> *— French patient*

extent, repigmentation and disease activity, there is currently no consensus on which instrument should be used.[88]

Therefore, the Vitiligo International Task Force for an Agreed List of Core Data (VITAL) project is developing and standardising core outcome sets, including measurement instruments for vitiligo clinical trials, registries and clinical practice worldwide.[89]

Furthermore, **the International Vitiligo Task Force recommends considering the use of quality of life (QoL) measurements in all patients and interventions.**[90]

In practice, only France, Germany, the Netherlands and Spain collect patient outcomes and/or feedback prior to follow-up visits, and even then, it occurs rarely.

To evaluate success of treatment, Belgium, Germany, Italy, Netherlands, Spain and the UK use clinical scores for dynamic evolution, measures of extent and/or repigmentation or static measure of clinical activity signs, followed by QoL questionnaires and patient-reported outcomes.

Moreover, SWG members in Belgium, France, Germany, Italy, the Netherlands and the UK generally agree that specific metrics should be included by HCPs in the evaluation and progression of vitiligo, especially in relation to vitiligo subtype, disease location, extent, activity and quality of life.

In clinical practice, however, they note that limited time during consultations means that current measurement tools are too time-consuming for routine use. As such, SWG members advocate for the development of new, quicker and easier to use measurement tools, or for improvements to existing ones.

> *"Time is very important when we consult patients. In the academic hospitals, healthcare professionals might have more time, but dermatologists in other practices will just have time to ask the patient how treatment is going, what the patient think about improvement or worsening of the condition. This is why we need recommendation on specific instruments to use in clinical practice. We should have such recommendations in place, but also create new instruments that are easy to use"*
>
> *— Dutch healthcare professional*

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[88] van Geel N, Duponselle J, Delbaere L, et al. Clinician-reported outcome measures for the assessment of vitiligo: A scoping review. *J Eur Acad Dermatol Venereol.* 2023;37(11):2231-2242.

[89] van Geel N, Hamzavi IH, Pandya AG, et al. Vitiligo International Task force for an Agreed List of core data (VITAL): study protocol of a vitiligo core outcome set (COS) and contextual factors for clinical trials, registries, and clinical practice. *Trials.* 2022;23(1):591.

[90] van Geel N, Reinhart S, Taïeb A, et al. Worldwide expert recommendations for the diagnosis and management of vitiligo: Position statement from the International Vitiligo Task Force Part 1: towards a new management algorithm. *J Eur Acad Dermatol Venereol.* 2023;37(11):2173-2184.

05

Policy Prioritisation and Reimbursement

STEP 5: Policy Prioritisation and Reimbursement

Policy Prioritisation and Reimbursement

KEY CHALLENGES

5.1 Lack of prioritisation is reflected in fragmented reimbursement schemes and out-of-pocket payments

5.2 Despite high costs, some are willing to pay the price for treatments out of their own pockets

5.3 Cost often bars access to non-pharmacological treatments

Vitiligo does not receive sufficient attention, leading to a substantial gap in the health policies designed to meet the specific needs of people living with this condition.

Despite recognition as a chronic autoimmune disease in national and/or regional policies in all reviewed countries except Belgium, there remains a notable lack of policies and comprehensive strategies to address patients' unmet needs and provide strong patient support, including access to new treatment options.

Although vitiligo research is recognised at the EU level within the broader category of immune-mediated diseases, which includes

"Although vitiligo is recognised as a chronic and autoimmune disease in France, many HCPs, including some dermatologists and authorities, are still considering vitiligo as a 'minor' or benign condition, and sometimes not even as a disease"

— French healthcare professional

both common and rare conditions[91], experts have highlighted that many HCPs and authorities still consider vitiligo a cosmetic disease, leading to lower recognition by health authorities.

5.1

Lack of prioritisation is reflected in fragmented reimbursement schemes and out-of-pocket payments

The management of vitiligo involves substantial direct and indirect expenses, which are paid by patients, caregivers, third-party payers, government agencies, and medical institutions.[92]

This procedure is complicated by reimbursement processes for both pharmaceutical and non-pharmaceutical therapies for vitiligo not yet being harmonised across Europe. This lack of standardisation leads to significant variations in the availability and affordability of treatments across Europe. Moreover, in many Western countries, third-party payers frequently categorise vitiligo as a cosmetic condition.[93]

No comprehensive studies assess the economic burden of vitiligo across Europe as a whole, with research being limited to only a few countries. Additionally, not all of these studies provide details on reimbursement of vitiligo treatment costs by national healthcare systems.

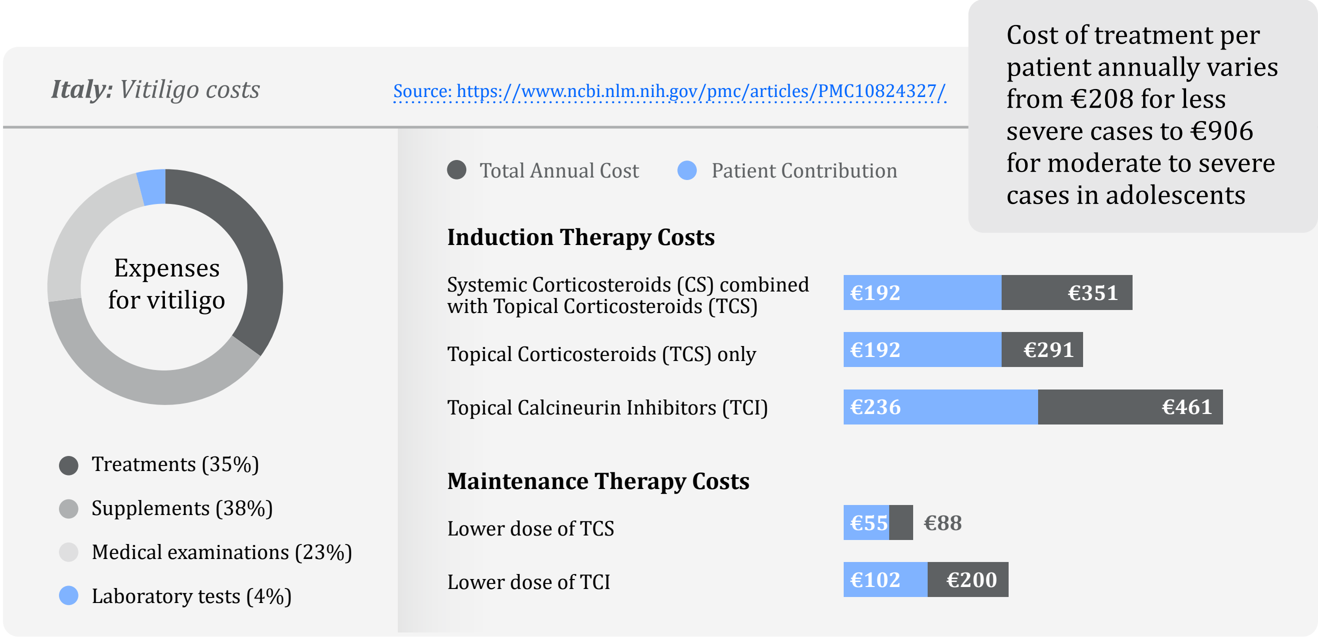
This lack of information (concerning the effectiveness of non-pharmacological methods, varied reimbursement processes across Europe and cost on national healthcare systems of vitiligo treatment) makes it difficult to assess the financial burden on patients. Other factors include:

- **Coverage of vitiligo treatments by private health insurance** varying from one policy to another
- **Prevalence of private health insurance differing across countries,** so the coverage that it offers for vitiligo treatments varies across the EU

This variation further highlights the disparities in access to treatments for vitiligo, depending on the prevalence and scope of private insurance in different regions.

Setting aside the impact of the treatment, the lack of reimbursement for pharmacological therapies for vitiligo remains a factor which significantly affects people living with vitiligo. Vitiligo treatments can be long-term, and expensive, with concern over cost often further exacerbating the challenges associated with managing the condition.

Managing vitiligo incurs significant costs, but this is especially the case for pharmacological treatments. For example, the total medical expenses for all patients with non-segmental vitiligo reach €80 million in Italy, with patients bearing the vast majority (95%) of these costs. [94]



***Italy:** Vitiligo costs*

Source: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10824327/

Cost of treatment per patient annually varies from €208 for less severe cases to €906 for moderate to severe cases in adolescents

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[91] Kyriakidies, Stella. Parliamentary Question, European Parliament 2023. Available at: https://www.europarl.europa.eu/doceo/document/E-9-2023-002338-ASW_EN.html (Accessed November 2024)

[92] Ezzedine K, Sheth V, Rodrigues M, et al. Vitiligo is not a cosmetic disease. *J Am Acad Dermatol.* 2015;73(5):883-5.

[93] Ezzedine K, Sheth V, Rodrigues M, et al. Vitiligo is not a cosmetic disease. *J Am Acad Dermatol.* 2015;73(5):883-5.

[94] Naldi L, Pagani A, Alduini C. Vitiligo: Epidemiology and Economic Impact. *Dermatol Pract Concept.* 2023;13(4S2):e2023315S.

Without coverage, especially for new therapies, the cost can become prohibitive for many patients, placing the financial responsibility of treatment squarely on their shoulders.

This makes it challenging for many to afford the continuous care that they need.

5.2

Despite high costs, some are willing to pay the price for treatments out of their own pockets

Vitiligo affects quality of life to such an extent that many individuals are prepared to spend large amounts on treatment. For example, approximately 32.5% of Germans living with vitiligo are ready to invest over €5.000 as a one-time payment for treatment. Additionally, 31.5% would be willing to spend more than €150 monthly for ongoing treatments, with the total average expenditures for complete vitiligo healing reaching up to €7.359.[95]

According to the surveys and interviews, the reimbursement landscape for different pharmaceutical treatments for skin vitiligo varies across the reviewed European countries, demonstrating the differing levels of support from healthcare systems.

Topical corticosteroids are reimbursed by national health systems in all of the reviewed countries, either fully (Germany, Italy, Netherlands and the UK), partially but complemented by private health insurance coverage adding up to full reimbursement (France), or partially (Belgium and Spain).

Topical calcineurin inhibitors are not covered by the Belgian and Italian health services, and the associated costs could restrict their long-term use for maintenance therapy. In Italy, this is because off label prescriptions are not reimbursed by the national health system. Oral steroid minipulse (OMP) therapy is fully reimbursed in all countries, except for Spain.

Topical JAK inhibitors are not reimbursed at all in Belgium, the Netherlands and the UK. In Spain, this therapy is only reimbursed through hospital pharmacy services. In Italy, the therapy is reimbursed for prescribing centres. Patients can also buy it in retail pharmacies, but in this case, they must pay out of pocket and will not be reimbursed by the national health system.

National health systems reimbursement[96]: Pharmaceutical treatment

	Topical corticosteroids	Topical calcineurin inhibitors	Topical JAK-inhibitors	Oral steroid minipulse (OMP) therapy
Belgium	🟡	🔴	🔴	🔴
France	🟢	🟢	🟢	🟢
Germany	🟢	🟡	🟢	🟢
Italy	🟢	🔴	🟢	🟢
Netherlands	🟢	🟢	🔴	🟢
Spain	🟡	🟡	🟢	🟡
UK	🟢	🟢	🔴	🟢

🟢 Full reimbursement 🟡 Partial reimbursement 🔴 No reimbursement

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[95] Radtke MA, Schäfer I, Gajur A. et al. Willingness-to-pay and quality of life in patients with vitiligo. *Br J Dermatol.* 2009;161(1):134-139.

[96] It must be mentioned that for this analysis, topical corticosteroids in Belgium have been marked as partially reimbursed given that none are specifically reimbursed for the treatment of vitiligo. Moreover, treatments in France have been marked as fully reimbursed because the cost is shared between Social Security and mutuelle, or private health insurance. While Social Security covers a portion of the treatment costs, the remainder is handled by the mutuelle. Almost every citizen in France has a mutuelle, ensuring that any additional costs are manageable. For those without private insurance, universal coverage steps in to provide necessary support, ensuring broad access to healthcare. In addition to this, tacrolimus 0.1% (TCI) can be prescribed and reimbursed in France since March 2024 under a compassionate prescribing framework, authorized by the National Agency for the Safety of Medicines and Health Products (ANSM) for a renewable 3-year period. On the other hand, in Spain, most treatments have been classified as partially reimbursed due to a small co-payment required from patients. The amount of this co-payment varies depending on the patient's age, contributing to a slight variability in out-of-pocket expenses.

All pharmacological treatments are reimbursed only in France. In Germany, private health insurance plans must cover at least the same services as government health insurance. However, people who have private health insurance can choose to remove certain services from their coverage according to their individual contracts, meaning they may not always receive reimbursement for certain treatments.

In the Netherlands, there is no distinction between the national health system reimbursement and private health insurance. There is only one national system that distinguishes between the outpatient system (extramural) and the hospital system (intramural), with the outpatient system applicable for all treatments.

In addressing barriers to accessing pharmacological treatments, participants in the SWG and PWG surveys and interviews **highlighted the importance of gaining official recognition for vitiligo as a disease and securing formal approval for treatments from relevant health authorities**, including for off-label topical calcineurin inhibitors in countries like Belgium and Germany.

Moreover, many responses emphasised the need for increased awareness among policymakers and healthcare institutions about the burden of vitiligo, including the cost, psychological impact and prevalence of vitiligo. At the same time, ensuring that all relevant stakeholders, including patient organisations, are involved in the reimbursement decisions is key.

> *“In The Netherlands, the main patient organization was an important player in supporting reimbursement of treatments for vitiligo”*
>
> *— Dutch patient*

5.3

Cost often bars access to non-pharmacological treatments

The lack of access to and reimbursement for non-pharmacological treatments has a profound impact on patients with vitiligo. Non-pharmacological treatments include: narrowband UVB (in office or home phototherapy), excimer lamp or laser, systemic antioxidants and psychological consultations.

This financial barrier impacts access to treatments often seen as essential for managing the condition effectively, addressing not just the physical depigmentation, but also the significant psychological impact of the condition.

Without financial coverage, the costs of these therapies become a substantial barrier, preventing many patients from accessing them. This can lead to delayed or foregone treatment, or exacerbate feelings of self-consciousness, anxiety and depression. Therefore, patients are often left without the necessary tools to cope with the emotional and social implications of the disease.

While there are only a handful of studies distributed among a few countries on the costs of non-pharmacological treatments for people living with vitiligo, there remains a clear picture of state of cost. For instance:

One UK study highlighted that the average cost per person is £600 for topical corticosteroids, £775 for narrowband ultraviolet B (NB-UVB) therapy, and £813 for a combination of topical corticosteroids and NB-UVB over a 9-month treatment course (based on available data in 2017) for the entire intervention arm. The adjusted incremental cost for the combination therapy is £1,932 per successful treatment compared to topical corticosteroids alone, while for NB-UVB alone, it is £3,336. Although NB-UVB is less costly than combination therapy, it is also less effective, which accounts for the higher incremental cost. However, it must be mentioned that these costs have been identified as part of an economic evaluation study of a pragmatic randomized clinical trial. [97]

In Switzerland, the average treatment costs for NB-UVB per patient for each over 5 years amount to €2,475 when administered in a hospital setting. This cost drops to €1,571 for NB-UVB treatments conducted at home and to €1,179 for ultraviolet A1 services.[98]

In Italy, UVB phototherapy has an annual total cost of EUR 4,077, with patients bearing EUR 3,947 of this cost. When UVB phototherapy is combined with topical corticosteroids or topical calcineurin inhibitors, the total annual cost increases to EUR 4,198, with EUR 4,014 falling on the patient.[99]

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97 Sach TH, Thomas KS, Batchelor JM, et al. An economic evaluation of the randomized controlled trial of topical corticosteroid and home-based narrowband ultraviolet B for active and limited vitiligo (the HI-Light Vitiligo Trial). *Br J Dermatol.* 2021;184(5):840-848.

98 Merkel TA, Navarini A, Mueller S. Differences in phototherapy among skin diseases and genders in real-life conditions-A retrospective analysis of the cumulative doses, numbers of sessions, side effects and costs in 561 patients. *Photodermatol Photoimmunol Photomed.* 2021;37(5):464-473.

99 Naldi L, Pagani A, Alduini C. Vitiligo: Epidemiology and Economic Impact. *Dermatol Pract Concept.* 2023;13(4S2):e2023315S.

Surveys and reconciliatory interviews with members of the Scientific and Patient Working Groups have also shown that there are less non-pharmacological treatments reimbursed than pharmacological treatments.

National health systems reimbursement: Non-pharmaceutical treatment

	Psychological consultations	Narrowband UVB cabins	At-home UVB treatment	Excimer lamp or laser	Systemic antioxidants
Belgium	🟡	🔴	🔴	🔴	🔴
France	🟡	🟢	🔴	🟢	🔴
Germany	🟢	🔴	🔴	🔴	🔴
Italy	🔴	🟢	🔴	🟢	🔴
Netherlands	🟢	🟢	🟢	🟢	🟢
Spain	🟢	🟢	🔴	🔴	🔴
UK	🟡	🟢	🟡	🔴	🔴

🟢 Full reimbursement 🟡 Partial reimbursement 🔴 No reimbursement

There are less non-pharmacological treatments reimbursed by private health insurance than pharmacological treatments. NV-UVB is the most commonly reimbursed therapy by private insurers from France, Germany and Spain. Psychological consultation and at-home UVB treatment are only covered in Germany, while excimer lamp or laser therapies are reimbursed only in France. However, in Germany, reimbursement will also depend on the individual contract of people who have private health insurance. Similar to the therapies covered by national health systems, systemic antioxidants are not reimbursed in any of the countries studied.

Private health insurance: Non-pharmaceutical treatment

	Psychological consultations	Narrowband UVB cabins	At-home UVB treatment	Excimer lamp or laser	Systemic antioxidants
Belgium	🟡	🔴	🔴	🔴	🔴
France	🔴	🟢	🔴	🟢	🔴
Germany	🟢	🟢	🟢	🔴	🔴
Italy	○	○	○	○	○
Netherlands	○	○	○	○	○
Spain	🟡	🟢	🔴	🔴	🔴
UK	🔴	🔴	🔴	🔴	🔴

🟢 Full reimbursement 🟡 Partial reimbursement 🔴 No reimbursement ○ Not applicable

In addressing barriers to accessing non-pharmacological treatments, members of the Scientific and Patient Working Groups underlined the need for increased awareness about vitiligo and its impact, especially among decision-makers and healthcare institutions. Moreover, it has been suggested that recognising vitiligo formally as a disease could help in improving the reimbursement of these treatments, as well as ensuring that all relevant stakeholders are involved in reimbursement decisions. In addition to this, more evidence from multi-centre randomised controlled trials to support the effectiveness of non-pharmacological treatments like systemic antioxidants is needed.

06

Policy Recommendations

Vitiligo is a chronic autoimmune disease whose impact reaches beyond skin deep. Too often misunderstood and misrepresented, its profound and long-term impact on people and society is not acknowledged.

People living with vitiligo often experience significant challenges and feelings of isolation throughout their interaction with the health system. This has been the common thread across the seven countries under examination in this White Paper, which has shed light on the abundant gaps in the diagnostic and care pathways - starting from lengthy delays due to underdiagnosis and misdiagnosis.

Taking a holistic view on the common challenges of the vitiligo patient experience, from awareness and pre-diagnosis, diagnosis and referral, treatment management and follow-up and access to treatment, the experts involved in this White Paper reached consensus on concrete recommendations to enhance the quality of life and health outcomes for the Europeans affected by this condition. The figure below shows the patient pathways with all identified challenges.

Awareness and pre-diagnosis

1.1 A lack of awareness and knowledge leads to misconceptions about vitiligo
1.2 Vitiligo's impact extends beyond the physical
1.3 Inconsistent training of General Practitioners on vitiligo remains a key issue
1.4 Clinical guidelines on vitiligo remain inconsistent across Europe

Diagnosis and referral

2.1 Patients face a prolonged and complex journey to diagnosis
2.2 Diagnosis time varies by years, not months
2.3 Misdiagnosis remains a prevalent issue in Vitiligo cases
2.4 People seek information upon diagnosis, but it remains elusive in many countries
2.5 Issues in accessing specialists are driven by more than time constraints

Treatment initiation and disease management

3.1 Vitiligo treatment remains a long road of trial and error
3.2 Patients are left without information on their treatment options
3.3 Comorbidities management advice is often rare or non-existent
3.4 Shared decision-making tools are not consistently applied

Follow-up and support

4.1 Treatment follow-up consultations are too often not part of routine care
4.2 The mental health impact of vitiligo is pressing, yet under treated
4.3 Patients rarely have access to information on clinical trials
4.4 No international registry for patients with vitiligo exists
4.5 No common consensus on how best to measure vitiligo activity

Policy prioritisation and reimbursement coverage

5.1 Lack of prioritisation is reflected in fragmented reimbursement schemes and out-of-pocket payments
5.2 Despite high costs, some are willing to pay the price for treatments
5.3 Cost often bars access to non-pharmacological treatments

Based on the challenges and priorities identified at every step of the pathway, consensus was reached on policy recommendations that could unlock actionable solutions.

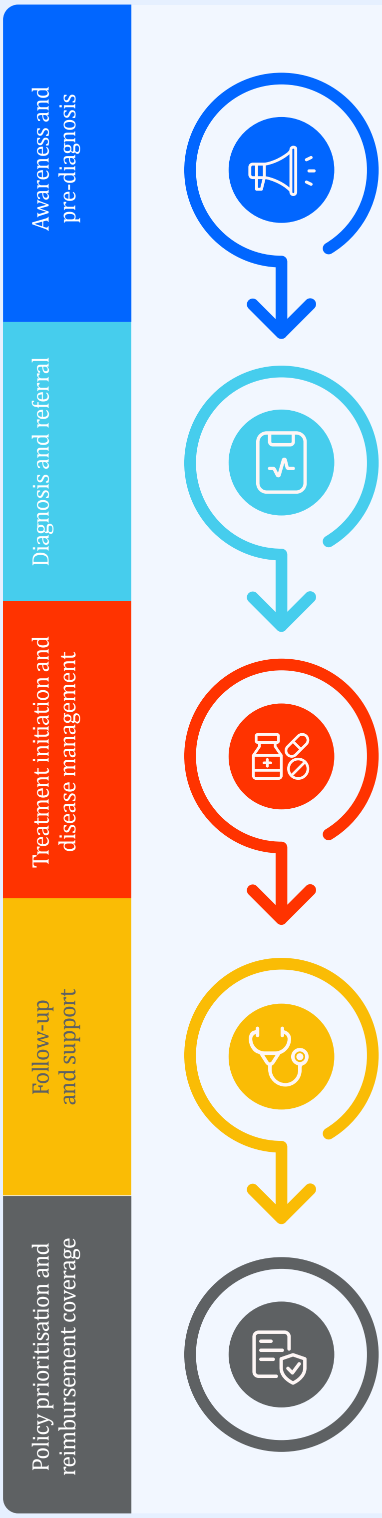
This White Paper focuses on actions that can be adopted either at the EU level or through regional collaboration to complement strategies that need to be developed and implemented at national level.

The policy recommendations are addressed to the following stakeholders:

- Regional, European and national policymakers (including WHO Region Europe bodies, European Union Institutions and national institutions)
- European and national medical societies representing dermatologists and other Healthcare Professionals
- European and national patient advocacy groups (PAGs)

On a European level, there are several initiatives that provide a framework for activation of the proposed recommendations. The Healthier Together – EU non communicable Diseases Initiative could act as a springboard for several initiatives to support EU Member States in implementing policies to reduce the burden of vitiligo and other autoimmune skin disorders. Another important policy platform that should be prioritised to drive action to address the mental health burden of skin diseases is the European Commission’s Comprehensive Approach to Mental Health, specifically combatting stigma and isolation of the groups that are most impacted by vitiligo (e.g. people with dark skin colour).

Hover over the steps to see a summary of the recommendations. You can read the full text on the next pages.



STEP 1

Awareness & Pre-diagnosis

The first step of the vitiligo patient pathway, as identified by the experts involved in the development of this White Paper, is awareness and pre-diagnosis.

To address the misconceptions of vitiligo, the lack of awareness of the symptoms and the disregard of its impact beyond the physical level, expert policy recommendations call on:

» **Policymakers to ensure that funding is available for campaigns on recognising the signs and symptoms of vitiligo, as well as on patients' unmet needs and the burden of the disease.** European and national medical societies and patient organisations should support the development and dissemination of educational materials and resources to help patients understand their condition, treatment options and the importance of managing comorbidities

» **European and national medical societies should ensure that there is integration of vitiligo into healthcare professionals' education,** notably on the medical curriculum for General Practitioners, as well as additional training programmes and continuing medical education (CME) for GPs and dermatologists

» **Medical societies and patient organisations at the European and national level should collaborate on interdisciplinary conferences, symposia and workshops on vitiligo, involving healthcare professionals and patients**

Funding programmes like EU4Health and the various programmes under the European Union's Cohesion Policy should continue offering opportunities for health stakeholders to develop awareness-raising initiatives and trainings for healthcare professionals.

STEP 2

Diagnosis & Referral

The White Paper shed light on the prolonged and complex journey to diagnosis, denoting on average a 2.5-year gap between patients first noticing lesions and receiving an official diagnosis, with wide variances between and within countries. Even more alarmingly, research reports that 3 in 7 individuals with vitiligo have previously received an incorrect diagnosis.[100, 101]

The information given to patients upon diagnosis is scattered and incomplete, and timely referral to specialist dermatologists remains a key challenge across the examined countries.

To address the significant delays in diagnosis and referral:

» **Medical societies should drive the creation of dedicated national/local referral networks and referral protocols,** in collaboration with national and subnational health authorities, to connect general practitioners (GPs) with dermatology specialists to accelerate diagnosis and streamline the referral process

» The model of the European Reference Networks (ERNs) that bring together European hospital centres of expertise should be explored to define criteria of excellence in skin health at European level, to connect national hubs and create hub-and-spoke models where the national hub serves as a coordinating entity with smaller centres.

STEP 3

Disease management (I) – Treatment initiation

Today, research reports that 65% of people diagnosed with vitiligo in Europe are told that their condition cannot be fully treated, and as a result, patients are left without information on their treatment options.[102] It is at this stage that many patients experience isolation, as they are often left to their own devices to seek out healthcare professionals who could offer a treatment plan. The care pathway therefore results into a trial-and-error experience.

In vitiligo, early treatment is particularly important as interventions are more effective at slowing or stopping the progression of pigment loss in the initial stages of the disease.

Moreover, due to the complex nature of vitiligo treatment, a combination of pharmacological and non-pharmacological treatment is frequently involved.

Vitiligo is linked to a higher occurrence of associated health conditions, yet literature reveals that patients face several bottlenecks in access to other specialists, with long waiting lists.

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[100] van Geel N, Harris JE, Hamzavi IH, et al. Exploring the Natural and Treatment History of Vitiligo in Europe: Findings From the Global VALIANT Study. Presented at 31st European Academy of Dermatology and Venereology (EADV) Congress, 7-10 September 2022, Milan, Italy, P1401.

[101] Bibeau K, Harris J, et al. Diagnosis and Management of Vitiligo From the Perspectives of Patients and Healthcare Professionals: Findings From the Global VALIANT Study. Presented at: Maui Derm for Dermatologists, 24 January 2022, Maui, HI.

[102] Bibeau K, Harris J, et al. Diagnosis and Management of Vitiligo From the Perspectives of Patients and Healthcare Professionals: Findings From the Global VALIANT Study. Presented at: Maui Derm for Dermatologists, 24 January 2022, Maui, HI.

To expedite treatment initiation, it is recommended that:

- **Medical societies should promote the integration and dissemination of the Worldwide Expert Recommendations, along with integrated care pathways,** to ensure coordinated diagnosis and management of vitiligo and its comorbidities. This may be achieved through vitiligo action groups within medical societies involving patient organisations, who can work closely with national policymakers
- **Policymakers and health authorities should ensure that protocols regarding patients' access to pharmacological vitiligo treatments support timely and appropriate treatment initiation**
- **Medical societies and patient organisations should encourage national policymakers and health authorities to include non-pharmacological treatments,** like psychological consultations, narrowband UVB, at-home UVB, excimer lamp/laser and systemic antioxidants in standard vitiligo care and reimbursement schemes
- **European and national medical societies, patient organisations, national health authorities and the relevant government ministries should define recommendations to raise awareness of available pharmacological and non-pharmacological treatments for vitiligo,** as well as their risks and benefits, and disseminate these among dermatologists and other healthcare professionals including general practitioners (GPs), paediatricians and nurses

The Healthier together – EU non communicable diseases initiative should provide the framework to develop initiatives to improve standards of vitiligo care across Europe.

STEP 4

Disease management (II): Follow-up and support

The limited implementation of the Worldwide Expert Recommendations on vitiligo results in a poor quality of follow-up care in Europe. Despite the known emotional impact of the disease on mental health, access to psychological support is rare.[103] The lack of registries and a common measurement framework also undermines research and policy decisions to improve vitiligo diagnosis and care.

It is therefore recommended that:

- **Medical societies and patient organisations (both national and European) should work to raise awareness among healthcare professionals and patients, in a coordinated manner and utilising existing groups such as the EADV Vitiligo Task Force, about the importance of follow-up care and how to manage the condition.** National and subnational health authorities should regularly review scientific advice to implement and update follow-up protocols
- **At both the European and national level, medical societies should promote and support the creation of patient registries to collect data on vitiligo cases and treatment outcomes (and comorbidities)**, which can be used to improve treatment protocols and management strategies and inform follow-up care practices
- **Medical societies and patient organisations should encourage international, supranational and national policymakers and health bodies to recognize and consider the psychological burden of vitiligo** in decisions on access to psychological consultations
- **European and national medical societies should support the implementation and use of standardised outcome measures for clinical practice,** such as the Core Outcome Set which is currently being developed by the Vitiligo International Task force for an Agreed List of core data (VITAL) group. National and subnational health authorities should also recommend their implementation in clinical practice

Besides a wider implementation of the Worldwide Expert Recommendations on vitiligo, the implementation of the patient registries should be promoted by EU and national policymakers as part of the implementation of the European Health Data Space and funded through EU direct (e.g. EU4Health, Digital Europe Programme) and indirect funding programmes (e.g. Cohesion Funds).

STEP 5

Policy Prioritisation and Reimbursement

The lack of prioritisation of vitiligo as a bespoke policy or a prioritized disease within the category of autoimmune skin diseases or non-communicable

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[103] Thompson AR, Delattre C, Khan I, et al. MENTAL HEALTH BURDEN RELATED TO PATIENTS WITH VITILIGO IN THE UNITED KINGDOM. *Acta Dermato-Venereologica.* 2023;103:14.

diseases results in fragmented reimbursement schemes and out-of-pocket payments.

The financial burden for pharmacological therapies for vitiligo remains a factor that affects people living with the disease and widens the social gradient whereby disadvantaged socio-economic groups have poorer outcomes because of health inequalities in access to treatment.

This financial barrier is even more pronounced for access to and reimbursement of non-pharmacological treatments, which are considered important by people living with the disease.

The White Paper Experts are therefore urging that:

- **Eligible patients should not bear the onus of non-reimbursed treatments.** National health systems, including statutory health insurances, should limit out-of-pocket costs as much as possible by providing full coverage of pharmacological and robust, peer-reviewed evidence-based (e.g. randomised control trial) non-pharmacological treatments
- **Policymakers and medical societies should ensure that national-level funding is available for research on areas including but not limited to vitiligo epidemiology, early signs, risk factors and strategies for early detection, translational and therapeutic research,** which are key to ensuring that screening and referral strategies are effective, standardised and implemented correctly. Furthering the understanding of pigment and cell disorder categories could also help advance the discovery of new therapeutic solutions for vitiligo.

To advance the understanding of vitiligo, and improve diagnosis and care across Europe, it is paramount that vitiligo gains official recognition as a disease, ensuring formal approval for pharmacological and non-pharmacological treatments from relevant health authorities.

At the EU level, EU policymakers and European medical societies should ensure that EU funding, such as through the EU's Horizon Europe, is available for the above.

Improving the patient experience with a focus on health outcomes and quality of life should be a shared responsibility of all the stakeholders that have been mentioned in this White Paper. Only through partnerships and joint efforts can we provide long-term solutions for people that get lost in health systems.

07

Conclusions

At its core, this White Paper set out to show a fundamental problem with how we perceive vitiligo.

The duality of the disease makes it one which simultaneously draws attention to those living with the disease, while fundamentally making those people feel entirely unseen by health systems and policymakers.

Vitiligo is a chronic skin disease, and one with an impact which reaches far beyond the visible aspect. It is a source of social stigma and psychological distress, driven by a fundamental lack of understanding among the public, policymakers and society at large.

This White Paper explores the profound impact of the condition on patients, their families, caregivers and society as a whole. It highlights the challenges faced by individuals living with the condition, the emotional and practical burdens placed on their families, and the broader societal implications.

Those living with vitiligo face a fragmented diagnostic and care pathway, leading to delays, misdiagnosis and other significant gaps in care, ultimately resulting in many individuals living with the condition feeling isolated and unsupported.

The findings of this paper point towards a different future, and if implemented can significantly improve outcomes for those living with the disease. Through a connected, seamless pathway we can change lives. It's that simple, and the key thing that must change is ensuring that every patient receives timely and continuous care.

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Limitations

In compiling this White Paper, several methodological limitations were encountered and they should be considered when interpreting the current findings. These limitations highlight the challenges of conducting comprehensive research within constrained timeframes and resource allocations.

Firstly, a significant limitation of this study is that all the data was sourced from only seven countries (Belgium, France, Germany, Italy, Netherlands, Spain and the United Kingdom), which may not fully represent the broader European region.

At the same time, the scope of the literature review was confined due to a rapid review approach, resulting in a limited number of articles being scrutinised. This approach, while efficient, may have led to the exclusion of potentially significant studies.

Additionally, the online surveys conducted in Belgium and Italy had limited participation, with only one representative from the Scientific Working Group responding, and notably, no patient representatives were involved. This lack of diverse input could restrict the perspectives presented in the survey results.

Furthermore, no reconciliatory interviews were conducted in Belgium, Italy and the UK. Therefore, some data discrepancies may have remained unaddressed.

Finally, during the e-Delphi process, consensus was determined with a 60% participation rate, which might not fully reflect the broader consensus that could have been achieved with higher engagement.

Acknowledgements

This White Paper has been made possible thanks to the invaluable contributions and support provided by several organisations and individuals. The project is an initiative of Incyte, driven by their vision to improve outcomes for people living with vitiligo.

Special recognition is extended to the members of the Steering Committee: Professor Dr Nanja van Geel, Professor Dr Thierry Passeron and Mr Jean-Marie Meurant; whose expertise and guidance have been key in supporting the development of this White Paper.

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Special thanks also go to the members of the Patient Working Group, who have always provided key insights and participated in several phases of the project: representatives of Association Française du Vitiligo, Deutscher Vitiligo-Bund e.V., Vitiligo.nl, Aspavit – Asociación de Pacientes de Vitíligo, The Vitiligo Society UK. Their perspective was key for this White Paper to come to fruition.

Lastly, appreciation goes to the project team, namely to the representatives of Incyte for driving this initiative; to Weber Shandwick Brussels, especially Marina Carzol, Daniela Negri, Megan Rowe and Karen Schober for coordinating and managing the project; Jules Johnston and Alanna Staunton for revising and editing the White Paper; as well as to Sarah Funderburk from Caudex for validating the different project phases.

Disclosures

The development of this White Paper was made possible through funding provided by Incyte. While Professor Dr Nanja van Geel and Professor Dr Thierry Passeron were only remunerated for their contributions to the phase one of this project as members of the Steering Committee (i.e. to advise on the methodology and framework), Mr Jean-Marie Meurant chose not to receive remuneration. It is important to note, however, that members of the Scientific Working Group and the Patient Working Group did not receive any compensation for their participation.

Annex

Detailed Methodology

Project governance

For the development of this White Paper, it was essential to ensure a robust and inclusive approach by consulting and involving representatives from healthcare professional (HCP) and patient communities in every step of the process. These representatives served as subject matter experts, thoroughly reviewing each phase of the study. Weber Shandwick, an independent consultancy, played a key role in overseeing the coordination, compilation and management of the project, ensuring that the contributions of all parties were seamlessly integrated and effectively utilised to inform the final outcome.

Objectives

This White Paper was specifically developed to identify and address gaps in the patient pathway for individuals living with vitiligo. By meticulously mapping out the journey that patients typically experience, from initial diagnosis to ongoing disease management, this document highlights critical areas where improvements are necessary, and proposes actionable solutions that can enhance patient care and outcomes.

Therefore, this project was undertaken with two primary objectives:

» To collect quantitative and qualitative data showcasing the current gaps in diagnosis and treatment of vitiligo, and demonstrate the full burden of the disease

» To recommend policy actions and other solutions to regulators, payers and healthcare providers to better address the psychosocial and societal burden of vitiligo

The Steering Committee (SC)

As detailed previously, a SC was established to guide and direct the necessary work in developing this White Paper and its recommendations.

The role of the SC was to:

» Align on overall objectives of the project

» Contribute to defining the proposed methodology

» Approve identified gaps (based on existing literature and from their own practice or experience)

» Validate the questionnaires for SWG and PWG consultation

» Define and vote on the policy recommendations through the e-delphi process

» Review, validate and endorse the White Paper

The final composition of the SC included two clinical expert in vitiligo, as well as patient representative:

Professor Dr Nanja van Geel
Professor Dr Thierry Passeron
Mr Jean-Marie Meurant

The Scientific Working Group (SWG)

Simultaneously, a SWG was formed to incorporate the insights of healthcare professionals into the process. This group consisted of clinicians specialising in vitiligo, alongside other relevant healthcare providers (including psychologist and pharmacists), all of whom have experience in treating individuals living with vitiligo.

The role of the SWG was to:

- Validate the methodology of the project
- Identify gaps along the vitiligo patient pathway based on their experience as HCPs
- Respond to the questionnaire on the identified gaps
- Provide additional qualitative insights via semi-structured interviews
- Define and vote on the policy recommendations
- Participate in a workshop discussing the findings of the White Paper
- Review, validate and endorse the White Paper

The final composition of the SWG included:

Professor Markus Böhm (Germany)
Doctor José Luis López Estebaranz (Spain)
Doctor Joaquín Borrás Blasco (Spain)
Professor Angelo Marzano (Italy)
Doctor Albert Wolkerstorfer (Netherlands)
Doctor John Ferguson (UK)
Doctor Anthony Bewley (UK)
Doctor Stephanie Gallard (UK)

The Patient Working Group (PWG)

Similarly, a PWG was formed to provide the perspective of people living with vitiligo. This group consisted of representatives of patient organisations from the key countries.

The role of the PWG was to:

- Be consulted throughout the process
- Identify gaps along the vitiligo patient pathway based on their own patient experience or the experience of members of their respective organisations
- Respond to the questionnaire on the identified gaps
- Provide additional qualitative insights via semi-structured interviews
- Provide a mandate to the Vitiligo International Patient Organizations Committee (VIPOC) to represent them and vote on the policy recommendations

The final composition of the PWG included representatives of:

Association Française du Vitiligo
vitiligo.nl
Deutscher Vitiligo-Bund e.V.
ASPAVIT Asociación de Pacientes de Vitíligo
Vitiligo Society EST 1985
Vitiligo International Patient Organizations Committee

The project phases

To accomplish the main objectives set out above, a structured research methodology was devised, comprising three distinct phases:

- **Phase 1:** Reaching consensus on the objectives, scope of the project and data collection methodology
- **Phase 2:** Data collection and analysis, which included:
  - Rapid literature review of publicly available sources of information/data for each country[104]
  - Overview of gaps and bottlenecks identified by the SC, SWG and PWG for each step in the patient pathway
  - Online structured surveys targeted at members of the SWG and PWG across the different countries[105]
  - Semi-structured virtual interviews with members of the SWG and PWG to reconcile discrepancies in the survey results for each country[106]
- **Phase 3:** Development of policy recommendations and White Paper, which involved:
  - An e-delphi process based on the careful development and iterative refinement of queries, leading to consensus being gradually achieved among all participants
  - Consolidation of findings in a comprehensive White Paper that outlines key gaps, best practices and recommendations for solutions and policy changes aimed at enhancing the care and, consequently, the overall quality of life of people living with vitiligo in Europe

Spotlight on Phase 1 – Defining data collection methodology

The overall methodology of the project and the data collection methods were defined by Incyte, Weber Shandwick and the SC over the course of several virtual meetings.

It was agreed that 7 countries would be covered by the report, namely: **Belgium, France, Germany, Italy, the Netherlands, Spain, the UK**

Spotlight on Phase 2 – Data Collection

Rapid literature review

A comprehensive rapid literature review was conducted to collect both quantitative and qualitative data on the care of individuals with vitiligo in the selected countries. This review included the analysis of 25 references, encompassing various sources such as:

- Scientific and academic articles, namely original articles (e.g. empirical research papers) and review articles (e.g. systematic reviews, literature reviews), as well as open-access publications
- Congress posters
- Information sourced from pertinent national organisations (considered grey literature), including governmental bodies, health authorities, medical societies and patient organisations

However, the review deliberately omitted certain types of content, such as methods or methodologies, clinical case studies, clinical trial papers, as well as notes and news items. Additionally, book reviews, perspective or opinion articles, and publications that required paid access were also excluded to streamline the focus of the data gathered.

Inclusion criteria for the literature review involved publications that were:

- Retrieved from Incyte's database or suggested by the members of the SC
- Focused on the 7 countries in scope
- Issued either in English or in any of their respective official languages
- Issued over the past ten years

Initially, a literature scan of the 25 references was made in order to define the main steps of the patient pathway, and to develop a form that could be shared with the SC and PWG to identify the main gaps and bottlenecks for each step. The following patient pathway was agreed by Incyte, Weber Shandwick and the SC:

- Pre-diagnosis / symptom recognition
- Diagnosis
- Disease management: treatment initiation
- Disease management: follow-up and support
- Cross-cutting topics

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[104] Smela B, Toumi M, Świerk K, et al. Rapid literature review: definition and methodology. *J Mark Access Health Policy.* 2023;11(1):2241234.

[105] Nigel G, Grant B, Raymond M. *The SAGE handbook of online research methods.* SAGE Publications ltd; 2016.

[106] Adeoye-Olatunde OA, Olenik NL. Research and scholarly methods: Semi-structured interviews. *J Am Coll Clin Pharm.* 2021;4(10):1358-1367.

Following the identification of gaps and bottlenecks, the literature review was revisited and the findings were summarised in English using a standardised template to ensure consistency. The results were organised according to the key themes and indicators outlined in the initial overview of gaps and bottlenecks.

Overview of gaps and bottlenecks

After conducting the initial literature scan, a standardised form was developed to systematically gather insights from SC and PWG members. Each member was asked to identify and submit the top three gaps and bottlenecks for each step of the pathway under review. The collected responses were meticulously analysed and categorised, resulting in the identification of 29 sub-indicators, which were further consolidated into 17 broader indicators. This structured approach ensured that a wide range of perspectives was captured and the most critical areas needing attention were pinpointed.

In line with the indicators identified and the rapid literature review, Incyte, Weber Shandwick, SC and SWG agreed to redefine the patient pathway as follows:

- Awareness and pre-diagnosis
- Diagnosis and referral
- Treatment management
- Treatment follow-up and measurement
- Access to treatment

Online structured surveys

Two online structured quantitative surveys were developed in English, targeting the members of the SWG and the PWG respectively. The primary goal of these surveys was to enhance the insights gained from the previous phases and to obtain a more comprehensive understanding of the diagnosis and treatment experiences of individuals living with vitiligo in the selected countries.

The SWG survey comprised 85 questions, whereas the PWG survey contained 84 questions. On average, participants took 112 minutes to complete the survey. Both surveys were available for a period of two weeks.

Below you can find a full breakdown of the number of respondents for each of the countries covered by the report:

	SWG members	PWG members
Belgium	1	0
France	1	2
Germany	1	0
Italy	1	1
Netherlands	1	1
Spain	2	1
UK	3	1

Reconciliatory interviews

In the two surveys that were launched, some discrepancies were noticed between the responses provided by members of the SWG and PWG. To address these inconsistencies and ensure a comprehensive understanding of the context and any nuances, as well as to reach a consensus, reconciliatory interviews were scheduled with experts from France, Germany, the Netherlands and Spain. Due to external factors, such interviews could not be organised for Belgium, Italy and the UK.

Each interview lasted 60 minutes and discrepancies were shared in advance to ensure a focused discussion. Attendance at each interview included at least one member from the SWG and one from the PWG who had participated in the surveys.

Spotlight on Phase 3 – E-Delphi consensus reaching

The Delphi method is a “structured communication technique and a systematic, interactive research method which relies on a panel of experts who answer questionnaires in 1-4 rounds”.[107] This iterative method aims to achieve convergence of opinion on specific issues.

In this context, the aim of the e-Delphi process was to reach a consensus among the SC and the SWG (the ‘panellists’) on actions/initiatives that should be taken either at the European level or across European countries by key actors, such as EU policymakers, WHO Europe, national policymakers, European and national medical societies, healthcare professionals and European and national patient organisations.

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[107] eDelphi.org. eDelphi 2024. Available at: https://www.edelphi.org/#:~:text=The%20Delphi%20method%20is%20a,questionnaires%20in%201%2D4%20rounds (Accessed October 2024).

The online platform edelphi.org, which is specifically designed for the qualitative application of the Delphi method, was utilised in this project. Throughout each round of voting, recommendations were refined based on the consensus of the group, ensuring that the final set of actions was comprehensive and broadly supported. For each round, a completion rate threshold of 60% was set. Four anonymous rounds of voting were carried out:

- **Round 1:** The panellists were provided with a list of potential regional solutions for the gaps identified in the previous rounds, based on solutions suggested by the SC, SWG and PWG members in meetings, survey responses and interviews. They were asked to prioritise those actions into one of three categories: top priority (actions that are urgently needed and would significantly impact that specific patient pathway), nice to have (actions that could be beneficial, but are not urgent or might not have a significant impact) or not a priority (actions that are unlikely to be helpful, are not urgently needed, or would not have a significant impact).
- **Round 2:** For each ‘top priority’ action identified in the previous round, participants were asked to specify which actors should be involved in implementing it: EU policymakers (European Commission, European Parliament, Council of EU), WHO/Europe, national policymakers (national governments, members of Parliament), European and national medical societies, as well as individual healthcare professionals and European and national patient organisations; participants could select multiple actors for one action / initiative.
- **Round 3:** Draft recommendations were formulated based on the results of the previous rounds and participants had to assess whether each recommended action / initiative is the optimal approach for the specified category of stakeholders to address existing deficiencies within a particular segment of the patient pathway; the voting process allowed participants to express their agreement or disagreement, and comment sections were included to capture insightful feedback, further suggestions or concerns.
- **Round 4:** A final virtual meeting with members of the SC and the SWG was organised to finalise those recommendations on which a consensus was still not achieved; a live, anonymous round of voting took place via the www.mentimeter.com platform.

VIPOC

Vitiligo International
Patient Organizations
Committee

About VIPOC

The Vitiligo International Patient Organizations Committee is a worldwide alliance of vitiligo patient organizations, established in 2018 during the first Vitiligo International Patient Organizations Conference, and is now an official NGO based in Paris.

Our mission is to enhance the daily lives of vitiligo patients by offering support and information, fostering understanding and recognition, and advocating for improved treatment and care from both the medical community and society.

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