VITILIGO SOCIETY
EST 1985

# STRATEGIC PLAN

vitiligosociety.org

# Contents

# Creating Our Vision for the Future

## Introducing Vitiligo

Vitiligo, also known as leucoderma, is a long-term (chronic) autoimmune condition that **causes areas of the skin to lose their pigment**. This occurs when melanocytes—the cells responsible for skin pigmentation—stop functioning, resulting in patches of skin appearing white or pink.

Vitiligo is one of the **most psychologically impactful** conditions in dermatology, as its effects extend far beyond skin pigmentation. The condition can develop at any age and in any individual, regardless of ethnicity or background. However, its visibility is more pronounced in individuals with darker skin tones. For those with fair skin, the loss of pigmentation may be less noticeable, making early detection more challenging.

## The Vitiligo Society

Established in 1985, The Vitiligo Society is the **only national charity in the UK** dedicated to supporting individuals living with vitiligo. **Our mission** is to combat the physical, psychological, and social effects of vitiligo by advocating for better awareness, supporting research, and working towards effective treatments and a cure.

## The Impact of Living with Vitiligo

In 2023, we launched the first UK research project to **uncover the true psychological and social effects of vitiligo**. We found that vitiligo significantly impacts individuals in three primary ways: ***Physically***, ***Psychologically*** & ***Socially*****.**

### *The Physical Impact*

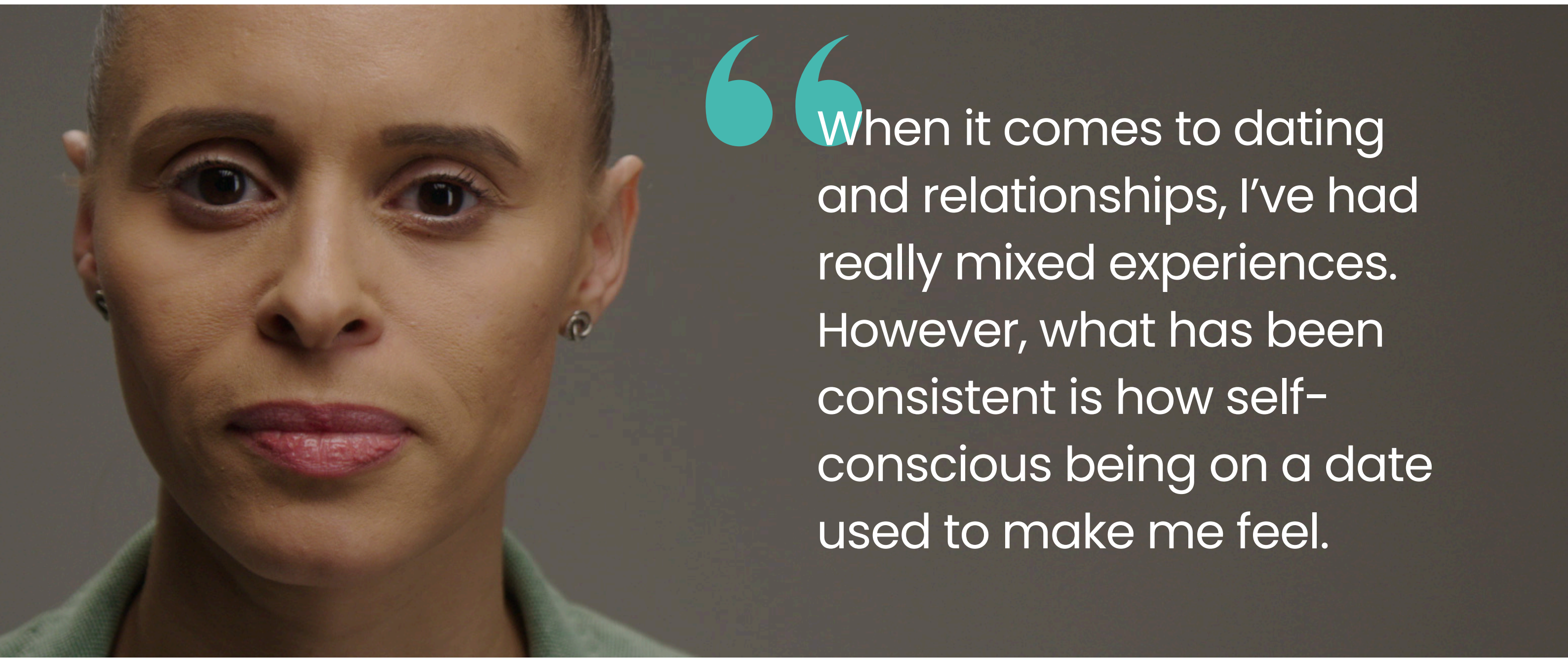
Beyond the conditions devastating visible effects, **32% of individuals report physical discomfort**, including itchiness, dryness, and pain. Patients can also experience increased sensitivity in affected areas can lead to sunburn and, in some cases, accelerated spread of depigmentation. Vitiligo is **linked to comorbidities such as autoimmune diseases**, diabetes, and joint disorders, yet routine testing for these conditions remains uncommon.

> People would say to me, “you look like a cow”. I would spend so much time covering my skin using brown markers.

### *The Psychological Impact*

Vitiligo **significantly affects mental health**. Patients often report feeling afraid of judgment and changes in their usual routine which contribute to diminished self-confidence and self-esteem. In addition:

- **79%** report a **negative impact on their appearance**.
- **63%** report **mental health challenges**, including stress, anxiety, depression, and feelings of isolation.
- **46%** experience **body image issues**, and 64% feel insecure or self-conscious.



> When it comes to dating and relationships, I've had really mixed experiences. However, what has been consistent is how self-conscious being on a date used to make me feel.

### *The Social Impact*

Vitiligo can often lead to social isolation, with **49% of patients reporting challenges in social interactions**. Key themes that emerge include:

- **Stigma and misconceptions:** Many individuals face inappropriate comments and misconceptions about vitiligo (e.g., "Did you put bleach on your skin?" or "Is it contagious?").
- **Workplace and relationship challenges:** 29% experience a negative impact on personal relationships, while 37% report difficulties in romantic and intimate relationships.

# THEORY OF CHANGE

It starts with...

**Our Mission** which requires us to...

Conduct **Research** to better understand...

**Your Priorities** which tell us where to focus...

**Our Objectives** which ultimately enable us to fulfill...

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# Why a strategy is important to us

Our research confirmed that vitiligo's impact spans physical, psychological, and social dimensions. To address these challenges, The Vitiligo Society is implementing a five-year strategy aimed at:

- **Enhancing medical support for vitiligo patients:** Advocating for increased screening, improved treatment access, and more holistic patient care.
- **Improving mental health resources:** Expanding peer support networks, providing educational materials, and fostering greater self-acceptance.
- **Fostering social change:** Raising public awareness, dispelling myths, and encouraging inclusivity through campaigns and community engagement.

By aligning our efforts with these core areas, we aim to **create a future** where vitiligo is widely understood, properly managed, and, ultimately, curable. Together, we can make a difference.

# Enhancing Medical Support

## What we know

Beyond the pigmentation loss, vitiligo can also cause physical discomfort. **Sun exposure** can exacerbate these symptoms, sometimes accelerating the spread of depigmentation. Vitiligo is also linked to the occurence of other autoimmune diseases.

Despite the clear need for treatment patients identified **five key barriers** which currently prevent them from accessing the medial support they need to treat their physical symptoms:

- A lack of any **clear, informative diagnosis**
- A lack of referral or a significant delay in **access to specialist services**
- Patients are not given a **structured treatment pathway**
- No access to **effective, licensed treatments**
- No testing for **associated autoimmune diseases**

> “Speaking to a GP who knows much about vitiligo and is empathetic about the condition is hard enough, but when I got to that point in my teens, I was told rather bluntly that there was no cure.

# Our objectives

## Ensuring a Clear, Informative Diagnosis and Treatment Pathway

Many vitiligo patients feel unsupported during diagnosis, with **only 4% feeling their concerns were acknowledged** by healthcare professionals. GPs often fail to provide sufficient information or referrals to specialists, leaving patients to seek answers on their own.

Misinformation and a lack of clear treatment pathways contribute to frustration and uncertainty. Patients struggle with long treatment timelines, inconsistent care, and limited awareness of available options, leading many to abandon treatment altogether.

**We aim to improve diagnosis experiences**, supporting patients to access to specialist referrals, and providing trustworthy information to help patients navigate their treatment journey with confidence.

## Increasing Access to Effective, Licensed, and Affordable Treatments

A major gap in vitiligo care is the lack of licensed treatments. Instead, patients are left with a confusing mix of unlicensed options, which can be costly, emotionally draining, and difficult to access.

**We aim to change this by advocating for better treatment options**, pushing for more UK based clinical trials, expanding access to licensed therapies, and improving NHS support for vitiligo patients.

# Our Projects and Activities

To enhance the medical support available to vitiligo patients we will focus on:

- **Conducting research** to better understand the unmet healthcare needs of vitiligo patients.
- **Enabling patients access support** throughout their healthcare journey.
- **Advancing research and treatment** development in collaboration with medical experts.
- **Educating healthcare professionals** to improve diagnosis, treatment, and patient care.
- **Campaigning for better treatment options** and improved access to care.

Through these initiatives, we aim to **transform the vitiligo care landscape**—ensuring that individuals receive the support, treatment, and recognition they deserve.

# Improving Mental Health Resources

## What we know

**79%** of patients reported vitiligo having a negative impact on their appearance, and **63% on their mental health**. This also included a **significant reduction in their quality of life**, feelings of isolation, sadness, frustration, stress, worry and depression.  **64% reported feeling insecure** or self-conscious about how their skin looks.

One of the **most prominent psychological effects is low self-esteem.** The **fear of being judged or rejected** due to appearance which impacts on day-to-day life and can also contribute to mental health conditions like **depression and anxiety**.

> “I just couldn’t tell my family that I had vitiligo and tried to hide away from the world. My confidence took the biggest hit.

# Our objectives

## Facilitating Peer Support Networks

With vitiligo affecting only 1% of the population, many patients inevitably feel **alone and isolated**. People living with vitiligo use a variety of coping strategies and resources to deal with their condition, a very important strategy that emerged from the conversations with our community was to **be able to talk to someone** about the condition and the challenges they face. However, many patients feel they lack the ability to speak freely about vitiligo, with people they trust and know are not going to judge them.

We will address this by **facilitating safe ways for people with vitiligo to connect**, and providing spaces where things related to vitiligo can be discussed.

## Ensuring Access to Information and Support Services

**33%** of patients report that it is **challenging to find information**. Even those that are able to find information easy report **uncertainty surrounding the information's accuracy**. People living with vitiligo want to know more about the condition than a healthcare practitioner has time to tell them. To understand the causes, how it can be treated, ways to self-manage and/or camouflage, associated health conditions, support services that can help, research updates, skincare and nutrition advice.

We aim to ensure vitiligo patients can find and access to **reliable sources of information**.

# Our Projects and Activities

To eradicate the psychological effects of vitiligo, we will focus on:

- **Be a trusted resource of vitiligo information** ensuring that patients can access information and that we use a network of experts to keep it relevant and up to date
- **Ensure the availability of peer support networks** to connect vitiligo patients and providing safe spaces for them to connect
- **Providing a platform** for experts to share information
- **Making referrals** to psychological and specialist support services

Through these initiatives, we aim to **create an informed, supportive vitiligo community** where any diagnosed individual is made to feel welcome.

# Fostering Social Change

## What we know

Vitiligo can significantly impact social interactions, with **49% of individuals reporting difficulties in their social life**. Many face negative reactions and misconceptions, with common questions including “Did you put bleach on your hands?” or “Is it contagious?” Such misunderstandings can lead to **isolation, loss of friendships, and missed job opportunities** due to fear of judgment.

Vitiligo also affects personal and intimate relationships, with **37% of individuals reporting difficulties in dating** and **sexual relationships** due to self-consciousness and fears of judgment. The social stigma surrounding vitiligo creates an **urgent need for greater societal awareness** to foster inclusivity and acceptance.

> I felt that people would be disgusted by my appearance. I used to hate thinking people were looking at me, so I would never lift up my face. I always kept my head down.

# Our objectives

## Raising Societal Awareness of Vitiligo

People living with vitiligo express a strong desire for **increased societal awareness** about the condition. They believe that more general awareness help to alleviate the negative impacts that can result from **misconceptions** and **stigmatisation**.

Currently patients report very little public awareness about the condition with many individuals feeling uncomfortable about, or unable to, go out in public.

We aim to combat this by running campaigns aimed at **raising awareness** and **increasing public understanding** about vitiligo.

## Addressing Social Inequalities in Vitiligo Care

Vitiligo affects everyone differently, however our research indicates that statistically there some demographics who are more likely to have a lower quality of life as a result of the condition. These groups include:

- **Individuals with medium to dark skin tones**
- **Those from culturally diverse communities**
- **Young people**
- **Individuals from low-income backgrounds**

**To support these communities**, we will strive to ensure that our outreach efforts and support services are targeted, inclusive, and accessible.

# Our Projects and Activities

To eradicate the social effects of vitiligo, we will focus on:

- **Conducting and sharing research** on the social impact of vitiligo.
- **Running awareness campaigns** to help educate the general public about vitiligo and overcome common misconceptions
- **Developing outreach programs** tailored to support the most affected communities.

Through these initiatives, we aim to **transform the way that individuals with vitiligo feel they are being perceived** by members of the public.

By increasing public understanding we can **create a more accepting society**, reducing the negative impact on those living with vitiligo. and enabling them to lead full and active lives again.

# PLAN ON A PAGE

## Our Mission

**To combat the physical, psychological, and social effects of vitiligo by advocating for better awareness, supporting research, and working towards effective treatments and a cure.**

## Your Priorities

**Enhancing Medical Support**

**Improving Mental Health Resources**

**Fostering Social Change**

## Our Objectives

- Ensuring a clear, informative diagnosis and treatment pathway
- Facilitating Peer Support Networks
- Raising Societal Awareness of Vitiligo
- Increasing Access to Effective, Licensed, and Affordable Treatments
- Ensuring Access to Information and Support Services
- Addressing Social Inequalities in Vitiligo Care

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# SUPPORT OUR WORK

Our charity work is enabled thanks to generous members of the public who donate from £2 a month to become a member of our charity.

Become a member of The Vitiligo Society

Make a one-off donation

Please consider supporting our work and helping us achieve the objectives set out in this document.

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