Exploring perceptions and experiences with Vitiligo

November 2023

Prepared for: The Vitiligo Society

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Introduction

The Vitiligo Society is dedicated to improving the support and wellbeing of those living with vitiligo. Through this research initiative, they are aiming to gain more understanding of the physical, psychological and social implications of vitiligo, and identify more effective initiatives to support those affected by the condition.

Although the first case of vitiligo was discovered hundreds of years ago, vitiligo is still not a widely-discussed condition, and a lot of difficult and educational conversations are necessary to ensure people understand what it is like to live with vitiligo. Vitiligo is a skin condition where the body produces less melanin – the pigment responsible for the colour of the skin, hair and eyes – and it can affect between 1% and 2% of the global population, regardless of gender, race, or age. While vitiligo may not always be visible, it holds significant implications for those living with it. This report aims to start a conversation around vitiligo and promote greater understanding and awareness, while also showing different experiences and the impact it has on people's lives.

Vitiligo presents distinctive challenges, not only to physical health, but also to mental and emotional wellbeing. It is widely considered as one of the most psychologically-devastating skin conditions, as it challenges societal norms related to skin pigmentation across various cultures[1]. This psychological impact extends to all individuals with vitiligo, regardless of their skin tone, underlining the importance of addressing the emotional consequences of the condition. In order to recognise and manage the impacts that vitiligo can have on quality of life and self-esteem, medical professionals—including general practitioners (GPs)—must be highly aware of the impact and attend to any mental health issues.

It is essential to recognise that our physical appearance, including our skin, significantly influences how we think others perceive us, which in turn impacts our overall wellbeing. Therefore, our research aims to bring to light the psychological struggles for people living with vitiligo, their views towards medical attention, and the various forms of support both available and sought after by people living with vitiligo. This comprehensive study involved the scoping of previous information and research, a survey that reached over 1,000 participants, 20 in-depth interviews, and a segmentation analysis, culminating in this report. Below you will find the primary findings and behavioural insights, which encompass the aspects of vitiligo that aren't really talked about in society, and the different ways the condition can affect someone, including interactions with others, daily routines, and self-perception.

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1. Grimes PE, Miller MM. Vitiligo: Patient stories, self-esteem, and the psychological burden of disease. Int J Womens Dermatol. 4(1):32-37.

Methodology

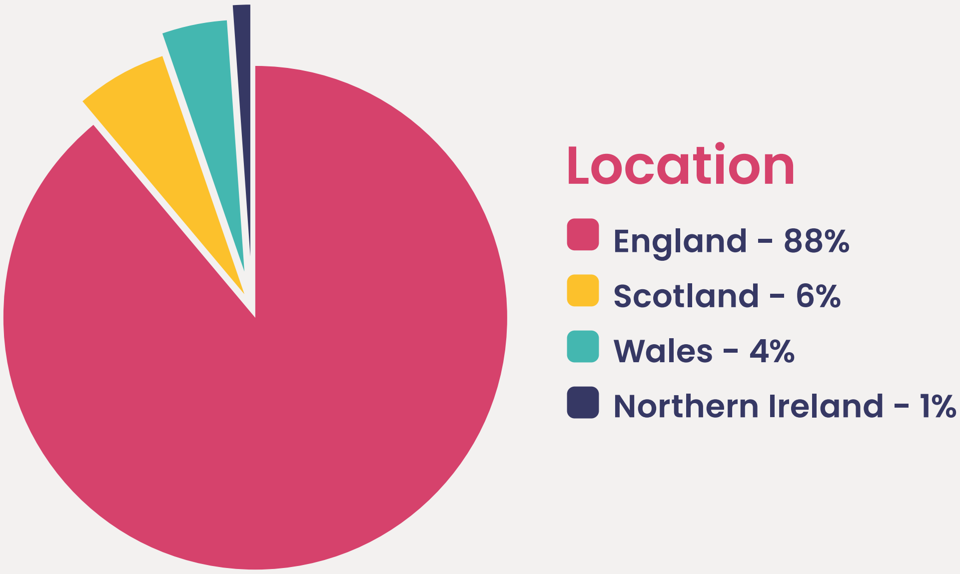
Scoping

To gain a general understanding of what it is like to live with vitiligo, we conducted a scoping exercise. This involved looking at existing information and data related to the characteristics of vitiligo and its prevalence, the difficulties and health inequalities people living with vitiligo face, physical, social and psychological effects, and previous research conducted on the condition.

Insights Survey

For this stage, we used all the information found in the scoping to create an insights survey, which was informed by the COM-B Model of Behaviour[2]. The insights survey aimed to find out more about the experiences of people living with vitiligo and the awareness of the condition in the general public, as well as the possible positive and negative impacts vitiligo can have on people's lives. These findings would allow us to identify and consider what support people living with vitiligo would find useful and how the Vitiligo Society could contribute to this. After cleansing the data, the survey had a total of 828 respondents, of which 712 were people living with vitiligo and 116 were non-sufferers. Below are some data breakdowns of the demographics of respondents who were identified as living with vitiligo. Please note that all percentages are rounded so may not appear to equate to 100%.

Fig. 1: General demographics of survey respondents living with vitiligo



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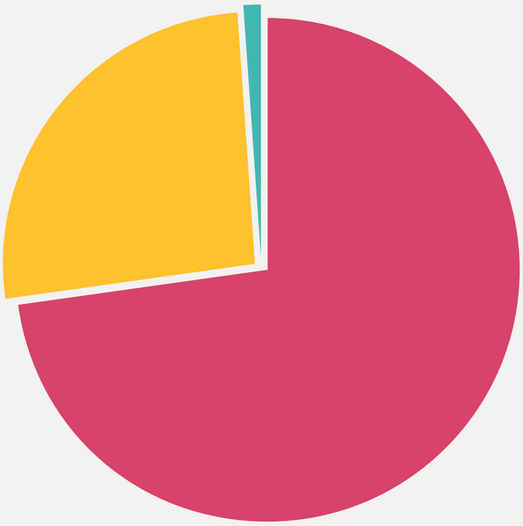
[2] Michie, S., Van Stralen, M. M., & West, R.(2011). The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implementation science, 6(1),1-12.

Age range

- ■ 16-24 - 3%
- ■ 25-34 - 10%
- ■ 35-44 - 18%
- ■ 45-54 - 24%
- □ 55-64 - 21%
- □ 65-74 - 16%
- □ 75-84 - 7%
- □ 85 or above - 1%



Gender

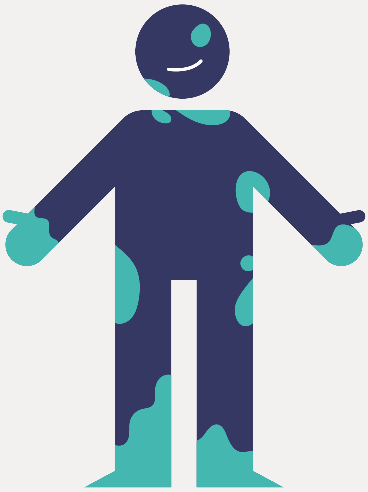
- ■ Female - 73%
- ■ Male - 26%
- ■ Other - 1%

Relationship to the Vitiligo Society

- ■ I'm a subscriber/follower but do not currently pay membership - 38%
- ■ I have been paid member, now or in the past - 31%
- ■ I've heard of it but do not subscribe/follow - 19%
- ■ I've not heard of it - 12%

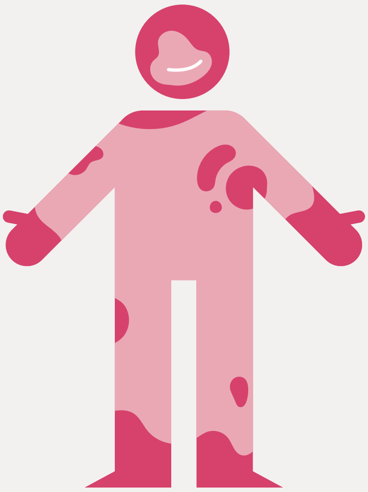
Fig. 2: Their vitiligo characteristics

Type of Vitiligo



Nonsegmental vitiligo (69%)
(i.e., symmetrical or affecting both sides of the body).

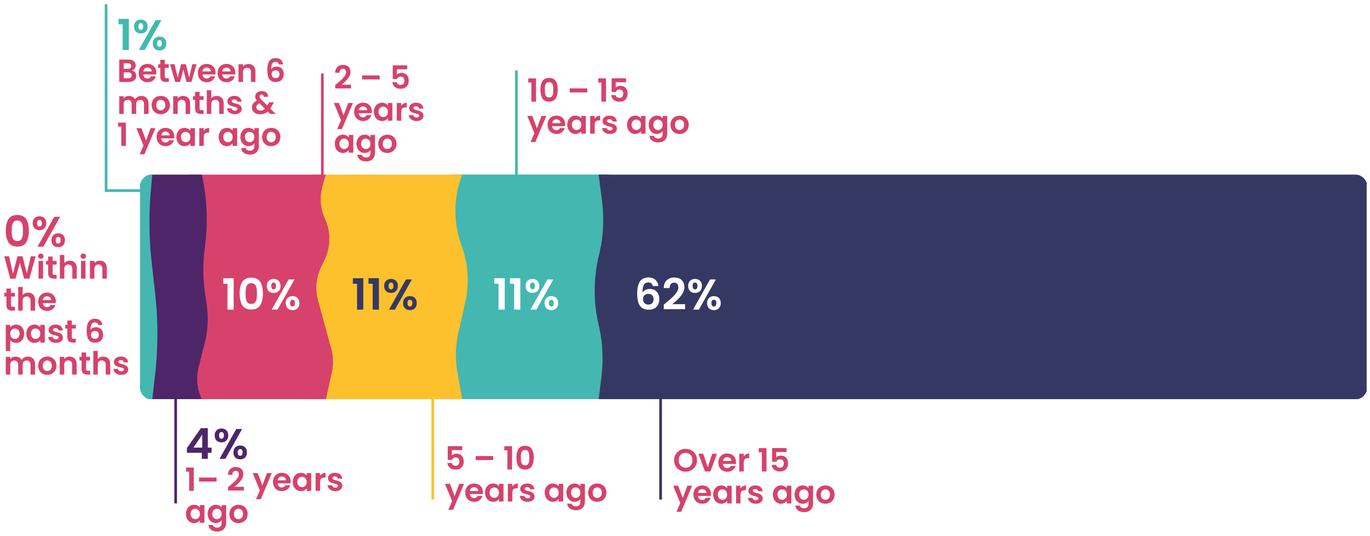
Segmental vitiligo (9%)
(i.e., unsymmetrical or affecting one side of the body).



Universal vitiligo (14%)
(i.e., the entire body is depigmented).

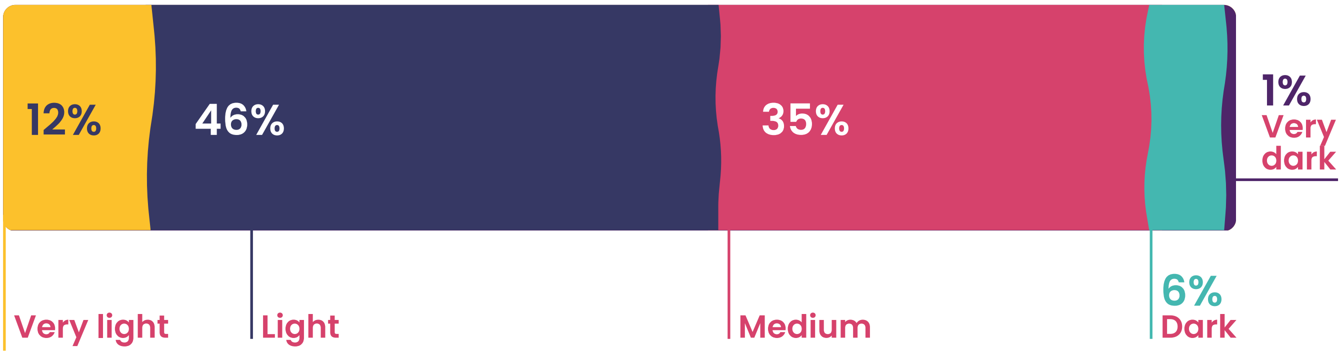
I'm not sure (9%)

When did you first experience vitiligo?

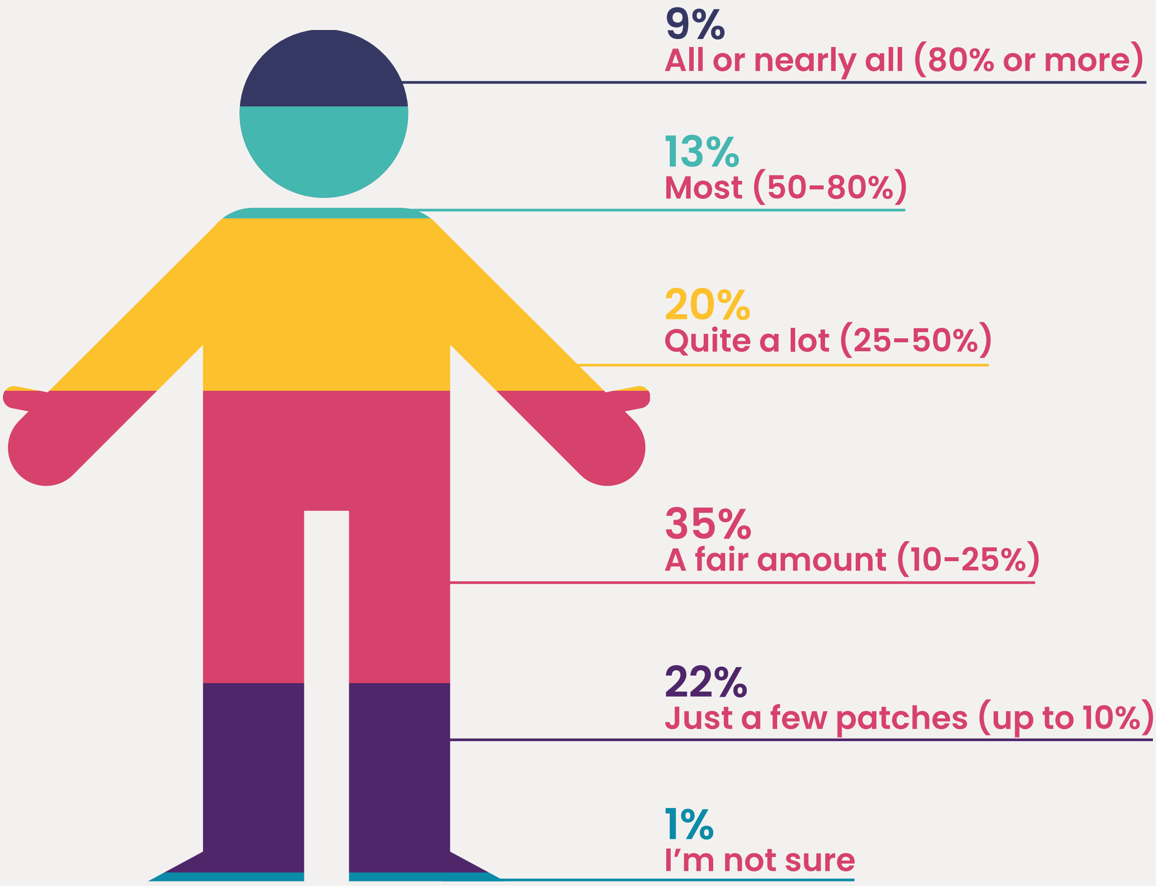


First person in their family to experience vitiligo

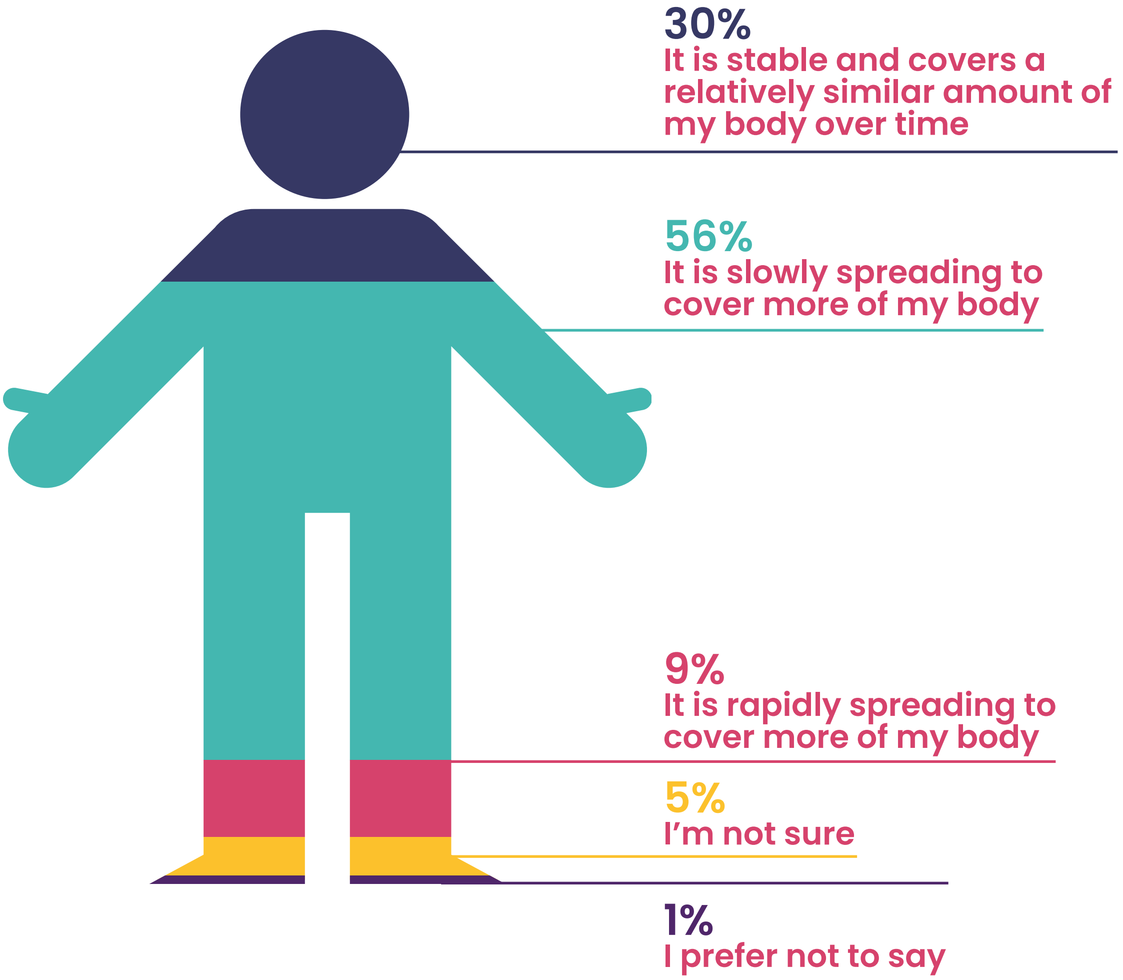
Skin colour



Amount of skin currently affected by vitiligo



How is your vitiligo currently changing or spreading in general?



Segmentation

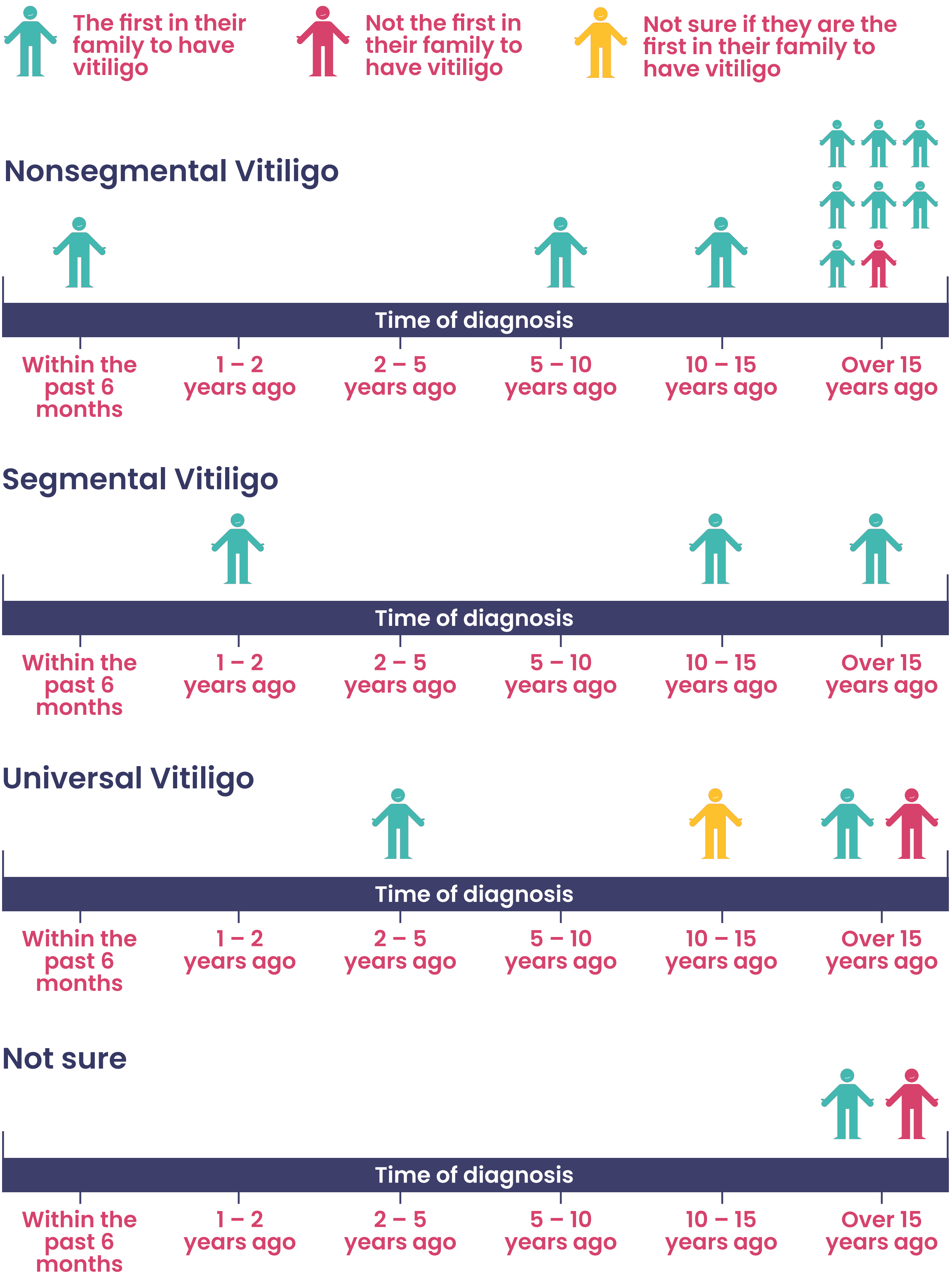
As part of the survey analysis, we conducted a segmentation exercise on the data relating to people identified as living with vitiligo to help us to understand their different attitudes and experiences. Segmentation is a statistical analysis which seeks to identify hidden trends in data, placing members of an audience into a number of sub-groups (or 'segments'). Whilst many conduct segmentation based on demographics, we do so based on shared characteristics, beliefs and behaviours, as this provides a richer understanding of audiences and their lives – cross-tabbing analysis is then used to consider the likely demographics of each group.

These segments provide insight into different groups within the audience, the varying experiences and challenges they may face, in addition to how they specifically could be best supported (e.g., through tailored messaging or service provision). Through this analysis, we identified three segments: (1) I'm getting on alright; (2) It is a struggle sometimes; (3) My vitiligo significantly impacts me.

Interviews

The survey provided valuable insights into people's experiences of living with vitiligo, their daily struggles and diagnosis journey. To further explore these insights, we conducted 20 in-depth interviews with people who opted-in to share more about their personal experiences. This stage allowed us to understand further what it is like to live with vitiligo and how the Vitiligo Society could enhance the support given to people living with vitiligo, including raising public awareness about the condition. Below is a breakdown of the vitiligo characteristics of those we interviewed.

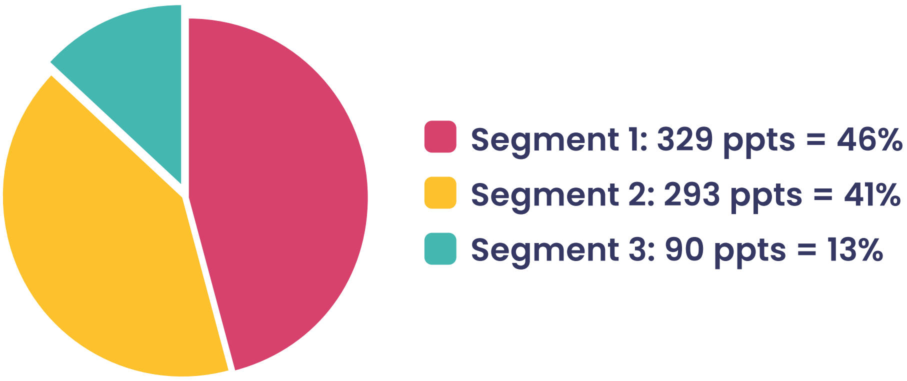
Fig. 3: Demographics of interview participants



Segmentation

Through segmentation, we were able to identify three sub-groups within the population of those living with vitiligo. These segments enable us to identify the different attitudes and experiences of people living with vitiligo, and its varying impact on their lives.

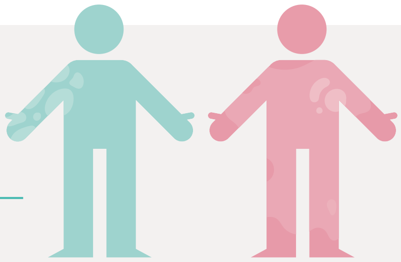
Fig. 4: **Distribution of respondents with vitiligo across each segment**



The following pages include an overview of each segment, detailing their likely demographics and experience of living with vitiligo.

Segment 1: I'm getting on alright

This segment is the least likely of all three to face significant challenges in relation to vitiligo. Looking at their typical demographic information, this could be due to the fact that they are more likely to have lighter skin, with research indicating that those with darker skin tones are more likely to be adversely impacted by their vitiligo (see page 10 [treatment]). This is in addition to the fact that this segment is more likely to be older in age, with this insight research highlighting that people seem to be more accepting of their vitiligo with age (see page 9 [diagnosis]). Generally, this segment's knowledge of vitiligo is okay, but they would be open to learning more about it.



Type of vitiligo: Likely to be segmental or universal

Skin colour: Likely to have light skin

Patches: Likely to have a few or fair amount of patches

Sex: Distribution of females to males is similar to the overall average

Age: Fewer people aged 35 - 54 than average, but more aged 55+

Segment 2: It is a struggle at times

This segment is likely to be somewhat impacted by challenges and concerns relating to their vitiligo. One of their biggest concerns is around their appearance and how others will react, which could link into the fact that they are likely to camouflage. This concern relating to their appearance is likely linked to the fact that a large portion of their body is likely to be affected by their vitiligo and that they have light-to-medium skin, with darker skin tones being linked to more negative impacts. Mental health is also a key challenge for this group, which in addition to their appearance is likely impacted by concerns about their health and adjustments they may need to take. Perhaps relating to the lack of support they feel despite facing negative impacts, this segment is likely to want a range of further information about vitiligo, even if they feel they have a good level of knowledge. Interestingly, this segment is also more likely than average to engage with the Vitiligo Society, reflecting this desire for more knowledge, but not necessarily pay for a membership.

Type of vitiligo: Likely to be non-segmental

Skin colour: Likely to have light to medium skin

Patches: Likely to have a fair amount to most of their body being covered

Sex: More females and less males than the average

Age: Similar to average age distribution

Segment 3: My vitiligo significantly impacts me

This segment is the most impacted by their vitiligo and the most likely to face significant challenges to their day-to-day lives, which may even limit their ability to do things they enjoy and subsequently impact their quality of life. The degree to which they are impacted is unsurprising when considering the fact that they are likely to be both younger in age and have darker skin compared to the other segments, two factors which have been linked to more adverse experiences in relation to vitiligo.

Whilst they face negative impacts across their lives, this mostly relates to their appearance (reflected in the fact that they frequently camouflage) and social life, the latter of which echoed effects in their relationships due to concerns and challenges around meeting new people, being intimate with others and how others will react and interact with them. These all contribute to their mental health, alongside the burden of having to think about the adjustments they need to make, whether they can participate in activities and the wider health impacts of vitiligo.

Contributing to the challenges they face is the fact that their experience with healthcare professionals is unlikely to be helpful or supportive, with them likely facing difficulties in accessing treatment. Perhaps because of these challenges and unhelpful experiences, this group want a lot more information about vitiligo.

Type of vitiligo: Likely to be non-segmental

Skin colour: Likely to have medium-to-dark skin

Patches: Likely to have a fair amount or quite a lot

Sex: More males and less females than average

Age: More people aged 35 - 54 than average and less aged 55+

Findings

Vitiligo is one of the most psychologically devastating diseases in dermatology because its significance extends far beyond skin pigmentation. While the most visible manifestations of vitiligo may be evident in racial and ethnic groups with darker skin tones, it is important to recognise that every individual living with vitiligo encounters some degree of emotional disturbance. It is important to mention that the lived experiences of individuals with vitiligo often share common threads and impacts, like changes in their daily lives, worries and concerns. The key findings are presented and categorised into the following:

- **Awareness and knowledge**
- **Vitiligo journey**
- **Overall experience**
- **Impact**
- **Suggestions for what can be done differently to improve the lives of those affected by vitiligo**
- **Coping strategies and resources**
- **What do people want to be different**

Awareness and knowledge

After being diagnosed with vitiligo, people tend to gain a lot of knowledge about the condition. Prior to their diagnosis, many individuals were not even aware of the existence of vitiligo (62%). However, after their diagnosis, more than half of them (57%) believe that they now have a good understanding of the condition. Nevertheless, this still indicates that many people living with vitiligo do not feel that they possess an excellent understanding of the condition, despite the increasing knowledge and research about it. They feel that there is still much to learn and understand about the condition. The difficulty of finding information related to vitiligo is one of the factors that contributes to this issue, with just under one-third (29%) finding it challenging to find information. Additionally, though another third (34%) considers it somewhat easy to find information, they feel the problem lies in the uncertainty surrounding the information's accuracy.

Insight!

Even though people living with vitiligo have a better understanding of the condition, there is still a need for more information, both for them and those living without vitiligo. Specifically, people want more knowledge about whether it can be caused by skin damage and/or if exposure to certain chemicals can lead to the condition.

The majority of people surveyed know that vitiligo affects any skin type, not just dark skin, and that it can affect various parts of the body, not just hands, face, and feet. People living with vitiligo mentioned wanting to know more about specific topics related to the condition. These include what causes vitiligo, how it can be treated, the side effects and effectiveness of treatments, ways to self-manage and/or camouflage the condition, health conditions associated with vitiligo, support services that can help people with vitiligo, new research findings about vitiligo, and skincare and nutrition advice.

Vitiligo journey

The purpose of this section is to understand the unique experiences individuals go through from the moment of diagnosis towards their pursuit of treatments and support. People with vitiligo often describe their journey as a process of acceptance, resilience, and hope. Although all journeys are different and shaped by personal circumstances, feelings around diagnosis, treatments, and support often share similar themes.

Diagnosis

A diagnosis of vitiligo is often a significant moment in an individual's journey, and the experiences surrounding it can vary considerably. While the majority of people (55%) first learned about the condition through a GP or healthcare professional, their overall experience with the diagnosis was often not reassuring or positive. Respondents mentioned and described feeling uninformed, unsupported, unheard, distrustful, and/or pessimistic when receiving the diagnosis. Similarly, other feelings such as neglect, confusion, dismissal, and fear were experienced to a lesser extent.

The journey with vitiligo is influenced by several factors, including an individual's previous knowledge of the condition, the age at which they received the diagnosis, and the type of vitiligo they have. It's very common for individuals to turn to a GP as their initial source of help and information, however the information received during this stage is often perceived as not useful and the possible psychological impact is not mentioned or addressed by medical professionals. People who are diagnosed with vitiligo from an early age tend to show a more positive relationship with their condition, embracing it as part of their body and self. In contrast, those diagnosed during their teenage years or later in life may face more challenges in coming to terms with the condition, due to the necessity of having to adapt to a new appearance.

> **"Initially it was really, really stressful to experience it because I didn't know what it was. And others around me didnt know about it either. And because I wasn't equipped with the right answers, I was bullied a lot as a kid. Other kids would tell me I was disgusting or I had a disease and they wouldn't touch me. The fact that the the GP didn't help at first really didn't make the situation any better"**
>
> **Male, 29 years old**

One prevalent issue that people living with vitiligo mentioned is often feeling dismissed and being told that it is only a 'cosmetic condition', which can be invalidating and frustrating. Additionally, many of them were not referred to a dermatologist or a specialist that could provide more information in relation to all aspects of the condition. People mentioned that being diagnosed only helped them understand what vitiligo is because they did a lot of research about it after being diagnosed. This could mean that there are many more questions than answers following a diagnosis with a GP. Unfortunately, participants reported that GP appointments in relation to vitiligo often lack certainty, reassurance and information about potential risks around related health conditions. In fact, only 4% of survey participants said that their diagnosis helped them to feel seen and heard by healthcare professionals.

> **"I just think that medical professionals don't know about it very much. They just really pass it off, so maybe they just need more education on what it actually is. The amount of times I've had to explain to a doctor what Vitiligo actually is and then they say 'ohh, that's fine you know, doesn't affect anything'"**
>
> **Female, 21 years old**

Treatment

The treatment journey for individuals living with vitiligo is a diverse and constantly developing process. It often starts with the diagnosis, during which healthcare professionals may provide and introduce information about potential treatments. However, as mentioned earlier, this diagnosis phase may not always offer the level of reassurance and guidance people need. This is why people described their treatment journey as sort of a 'trial-and-error' process, while exploring different treatment options.

> **"But there's one thing I am really disappointed about and it's people do spend a lot of money on treatments that don't do anything"**
>
> **Male, 40 years old**

This process can vary significantly depending on the type of vitiligo, location and colour of the patches, the extent of their vitiligo, as well as individual preferences, goals and needs. For instance, some individuals opt for treatments focused on repigmentation, aiming to restore the colour of the depigmented areas, and may explore options like topical corticosteroids, phototherapy, or advanced therapies such as an excimer laser or microskin. Others may choose treatments to help conceal or camouflage depigmented skin, like using makeup or getting tattoos. The choice of treatment can also be influenced by an individual's psychological and emotional readiness to accept their condition.

This trial-and-error journey is often influenced by online information and social media, but it's important to note that what works for one person may not be effective for another, leading to potential frustration. People feel they must exercise a lot of patience and persistence, as treatment outcomes may take time to become evident. Some people mentioned how finding the right treatment for them, trusting it, and using it constantly can be emotionally challenging, time consuming, expensive, and sometimes difficult to access. This is why some individuals may choose not to pursue treatment at all, opting to embrace their appearance and find ways to boost their self-esteem and self-acceptance without medical intervention.

Interestingly, despite differing relationships with their vitiligo and whether or not they wanted treatment, almost all of the participants (75%) expressed a shared desire for a cure for vitiligo, and 15% expressed being resigned from finding a cure. This is why emotional and psychological support is crucial for people living with vitiligo throughout this diagnosis and treatment journey.

Support

Vitiligo has a profound impact on all aspects of an individual's life, emphasizing the crucial role of support from those in their immediate circle. People with vitiligo experience a sense of security and companionship when they have a support system and feel that their loved ones abstain from criticism or judgment. Many of them naturally seek the support of their close family and friends.

While this social support is important, there are other forms of support, particularly psychological support, which are not as frequently sought. Lack of seeking psychological support highlights its importance as a necessary tool that has proven to be beneficial for many and has the potential to help others who are struggling with the condition in the future.

Overall experience

The overall experience of individuals living with vitiligo is very varied, and influenced by multiple factors, including their individual characteristics, level of self-esteem, age, the extent of their support system, and how long they have had the condition. It is important to mention that all experiences are valuable and unique.

As mentioned, people's experiences depend greatly on individual characteristics. Some of them have had a difficult time accepting their condition and are now coming to terms with it, while others have always found it challenging to deal with and continue to struggle. Others have found ways to make the experience more bearable, while some are still trying to find the best coping mechanism for them.

"Vitiligo makes you tough", is a prevalent idea of what it is like dealing with the condition. Many individuals with the condition transform the negative side of vitiligo to a positive one, looking at it as an opportunity for personal growth and acceptance of the condition. But this is not the universal rule, and this quote only shows the far greater impact the condition can have in someone's life. Vitiligo forces some people to work on their self-acceptance and develop resilience, but it is a daily struggle to navigate and deal with all the challenges that come along with the condition.

Some characteristics have been identified that are associated with people feeling better able to cope with their vitiligo, such as having a higher self-esteem, being of an older age, having a strong support system, having hidden patches, and having a lot of time to adjust the condition. Individuals with higher self-esteem tend to experience fewer psychological effects associated with vitiligo, as they often exhibit greater emotional resilience and coping strategies, resulting in a positive self-image. Additionally, elderly individuals tend to have a more positive perception of life and a greater acceptance of their condition, having reached a level of self-assuredness that helps them cope with their vitiligo. They often focus on the value of their life experiences, rather than the negative impact of their vitiligo in their life.

> **"I just think as I've got older, I've kind of just become a bit more accepting of it"**
> **Female, 30 years old**

The duration of the condition also plays a role in the journey. Those who have had vitiligo for an extended period often go through stages, starting with struggling to accept the condition, trying to conceal it, and seeking self-improvement, before ultimately reaching acceptance. In contrast, people who have been recently diagnosed may experience feelings of denial, questioning why vitiligo is happening to them and feeling overwhelmed by the change in their appearance.

People living with vitiligo often make significant adjustments to their daily routines, with wanting to be able to leave the house without constant worry about their appearance. They may need to spend a lot of money on skin care products, apply sunscreen constantly, use camouflage techniques, and cover their bodies with specific clothing to protect their skin from sunlight. All these adjustments help them regain confidence and peace of mind. However, participants mention that this is not enough and with a further understanding and acknowledgement of this diversity, society can better support them and help them embrace their uniqueness.

Impact

Psychological impact

People living with vitiligo often experience a range of psychological effects. For example, 79% reported it having negative impact on their appearance, and 63% on their mental health. This also included a significant reduction of their quality of life, feelings of isolation, sadness, frustration, stress and worry, difficulty in relationships, depression and anxiety, body image issues (46%), and a lack of confidence. A further 41% struggle with their self-estem and 64% feel insecure or self-conscious about how their skin looks. One of the most prominent psychological effects is low self-esteem, which can lead to negative thoughts about appearance and patches, notably their characteristics, changes and spread, all of which impact self-confidence.

> **“You know, people say, ‘oh it’s not that bad, don’t worry, you can’t really see it’. But I know what I see in the mirror, so I have my own feelings on it”**
>
> **Male, 62 years old**

The fear of being judged or rejected due to appearance and changes in normal routine (e.g., having to avoid sunlight) can also contribute to mental health conditions like depression and anxiety. Social stigma, in particular, is a significant factor that can lead to social isolation due to avoiding social interactions and fearing negative reactions and comments from other people. This can be particularly challenging for individuals who experienced bullying and stigmatisation in their early years and are currently experiencing the lasting psychological effects of this, as some of them still remember being rejected and bullied for their condition.

“When I was younger, I think people were more mean about it because with kids in schools, they see something different and they kind of tend to pick it out and notice it more. But as I got to high school and grew up a bit, people started noticing it less. But I found that I still noticed because I knew it was there. So I guess that’s always been a kind of insecurity”

Female, 21 years old

Physical impact

In addition to the visible depigmentation of the skin, some people living with vitiligo also experience some physical discomfort (32%). Although itchiness, dryness and painfulness were not commonly reported, participants did mention a heightened sensitivity in the affected areas. In some cases, these areas are more sensitive to sunlight, which results in burns, with some reporting that it can make the patches spread faster. Although not resulting in physical discomfort or pain, the visible skin changes can have a significant impact on individuals’ lives, as highlighted in the previous section. Additionally, some physical health issues can be linked to vitiligo, even if these are not direct effects of the condition. There is a risk and potential for comorbidities, such as autoimmune diseases, diabetes, other skin conditions, and joint and connective tissue disorders like arthritis. It is important to mention that these are not experienced by everyone living with vitiligo, and the risks vary from person to person. Regular check-ups and talking to healthcare providers about these risks are therefore recommended.

Social Impact

Vitiligo can have a significant impact on an individual’s social life (49%), often leading to isolation and difficulties with social interactions. The majority of participants mentioned negative reactions and misconceptions about the condition, such as comments like “did you put bleach on your hands?” or “is it contagious if I touch you?”. Some Individuals may experience the loss of friends and missed job opportunities due to fears of being judged and withdrawing from social gatherings (29% reported noticing a negative impact in relationships with family and friends). However, some mentioned that the condition was eye-opening about who their real friends are and who supports them regardless of their condition.

Another important social impact to mention relates to personal and intimate experiences. 37% noticed an impact on their intimate and romantic relationships, such as dating and sexual encounters, which can also bring concerns regarding possible judgements and important conversations with partners. The condition often necessitates open and honest conversations with partners which, while challenging, can have a positive outcome by empowering individuals living with vitiligo and improving their self-perception. Navigating the social aspects of vitiligo is seemingly made easier with increased resilience, self-acceptance, and a supportive social network.

Familial impact

Family is one of the most important factors in accepting the condition and dealing with its negative effects. The prevalence of vitiligo within a family can significantly influence the experiences and perceptions of those living with the condition. Individuals who have family members with the condition tend to feel more accepted and grow up with the notion that it is okay to be different, often reducing negative thoughts and self-perception. Understanding the condition from an early age and having a supportive family helps individuals grow up with greater acceptance and a more positive self-image, as well as being more empathetic and develop more coping strategies. Knowing someone with vitiligo allowed people to feel less alone, often finding it easier to accept their own condition. Family is also a crucial source of support for those living with the condition, regardless of whether another family member has vitiligo or not, and individuals in stable relationships tend to handle the challenges of vitiligo more effectively.

> **“My family has been always supportive, they have never been negative about it [the condition]. Like they really see the beauty in me”**
>
> **Male, 33 years old**

Coping strategies and resources

People living with vitiligo use a variety of coping strategies and resources to deal with their condition. Most of them are doing things daily that they hadn't really realised are coping strategies, and mentioned taking one day at a time. However, it is important to recognise the effort that this implies to continue the process with resilience. A very important strategy that emerged from the conversations with participants was to be able to talk to someone about the condition and the challenges they face – participants felt like this was a weight lifted off their shoulders. Speaking freely about vitiligo, with people they trust and know are not going to judge them, is usually a good way of both normalising the condition and allowing people to be heard.

> **"I remember being very upset about it when I was younger because I felt very, very different to everyone, but I've learned to cope with it in different ways"**
> **Female, 21 years old**

Physical activity was also reported to be one of the best ways of coping with vitiligo, with people that exercise often having a more positive perception of their body, which helps to improve their self-image. Additionally, people mentioned using activity as an excuse to leave their houses and socialise more. People that utilise this strategy as a way of coping highly recommended it for people that are struggling with vitiligo.

Many participants mentioned wanting to find a wider community of people with vitiligo to hear people's experiences and help one another. This, in itself, is a good coping technique that allows a sense of community that is beneficial for general emotional wellbeing. Having a support group where things related to vitiligo can be discussed is an opportunity to learn from others and relate to their experiences. Indeed, those who had this opportunity through psychological therapy and counselling reported improvements in different areas of their life, including stress and anxiety management and self-esteem.

> **"Therapy in Cardiff is between 50 and 100 pounds a session. I think cost is definitely a barrier. I think people thinking 'well I can have all this therapy but at the end of the day I'm still going to have my vitiligo'. I really struggle with my self esteem, particularly like in relationships and I've had some therapy, but it hasn't been specifically dedicated to my vitiligo"**
> **Female, 35 years old**

Knowledge and advocacy are strategies and resources that people living with vitiligo often use to reduce the negative impact their vitiligo can have on their lives. Some people reported becoming advocates for vitiligo awareness and support, and mentioned being open when other people start conversations about their vitiligo from a curious point of view. These people engage in activities aimed at reducing stigma, educating the public and expanding a greater understanding of what vitiligo is. This, as a result, includes not camouflaging and showing their patches proudly. Another resource people living with vitiligo could be made more aware of is the Equality Act of 2010. Although skin conditions like vitiligo are not automatically classified as a disability, people living with vitiligo can be protected under the Act.

Finally, other resources people living with vitiligo use, and would recommend others use, include wearing clothes that make them feel comfortable, journaling, normalising the condition with their close friends and family, practice using positive affirmations, and arts and creative activities, as therapy methods and to socialise and connect with others. These coping strategies and resources can help individuals with vitiligo lead fulfilling lives, manage the challenges of the condition and improve their general wellbeing.

What do people want to be different?

People living with vitiligo express a strong desire for increased societal awareness about the condition. They believe that more general awareness will foster a more inclusive and accepting society which can help them feel more supported and alleviate the negative impacts that can result from misconceptions and stigmatisation.

In particular, they would like this awareness and understanding increased in the healthcare setting and among professionals. They hope in the future, healthcare providers will be more knowledgeable and informed about the condition, the range of available treatments for both repigmentation and psychological therapies, and the available support services for them. Most importantly, people with vitiligo would like to feel that healthcare professionals value and acknowledge their condition in a holistic way, considering that there is a whole world of other effects on the individual beyond its aesthetic aspects.

> **“They can’t explain why we’ve got it. They can’t explain. There is no cure. So I do understand that. But they don’t sort of give you any hope at all. They’re like, we can try this cream, but it’s probably not going to work. You can try this, but it’s probably not going to work. I know they’re trying to manage our expectations, but it very much is that you’ve suddenly been told you’ve got a condition that you don’t want, that affects you. They can’t tell you why you’ve got it. They can’t tell you how to stop it”**
>
> **Female, 50 years old**

Awareness of the psychological aspects of vitiligo and addressing mental health issues are highly valued for people living with the condition. Intervention strategies should aim to dispel myths and misconceptions surrounding vitiligo, highlighting that the effects on oneself are not only a cosmetic concern. In this regard, people mentioned a need for accurate and truthful information about vitiligo, the development of new treatments, and, ultimately, finding a cure for vitiligo.

> **“You’ve just gotta run with it and you get the feeling if you do try and question it, or try and work a way, you always have that feeling that there must be something I can do or what am I doing wrong?”**
>
> **Female, 50 years old**

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