



Vitiligo Support International

Searching for the cure one piece at a time

2000: Vitiligo Support began as an online grassroots support system where those with vitiligo could come together and discuss their daily challenges with others who understood.

2004: With nearly 30,000 registered members, Vitiligo Support incorporated, and became **Vitiligo Support International**, a 501(c)(3) nonprofit patient advocacy organization.

No longer just a website, or a support group, as a nonprofit organization, we've worked very hard to transition to a higher, national level of representation, with a greater emphasis on *education, research and advocacy*, and broadened our foundation by *increasing professional partnerships* and collaboration with the world's foremost leaders of the *scientific, medical, and professional* communities.

Today - With over 60,000 registered members from over 200 countries VSI has Become a Leader in Patient Support, Education and Outreach.

Vitiligo Support International
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VSI Partnerships

- *American Academy of Dermatology*
- *Coalition of Skin Diseases*
- *Skin of Color Society*
- *National Coalition of Autoimmune Patient Groups*
- *National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Coalition*
- *The PanAmerican Society for Pigment Cell Research (PASPCR)*
- *Society for Investigative Dermatology*
- *Women's Dermatology Society*
- *Vitiligo International Patient Organizations Committee*

The Voice of the Patient

One of VSI's paramount goals in the development of partnerships, has been to make sure that the **VOICE of the PATIENT is Heard and Understood.**

Over the decades we have communicated with thousands of patients who've shared their experiences, fears, frustrations, and heartbreaks. It is through these stories that we have been able to keep our finger on the pulse of the real-world, day-to-day impact on the lives of those affected by vitiligo.

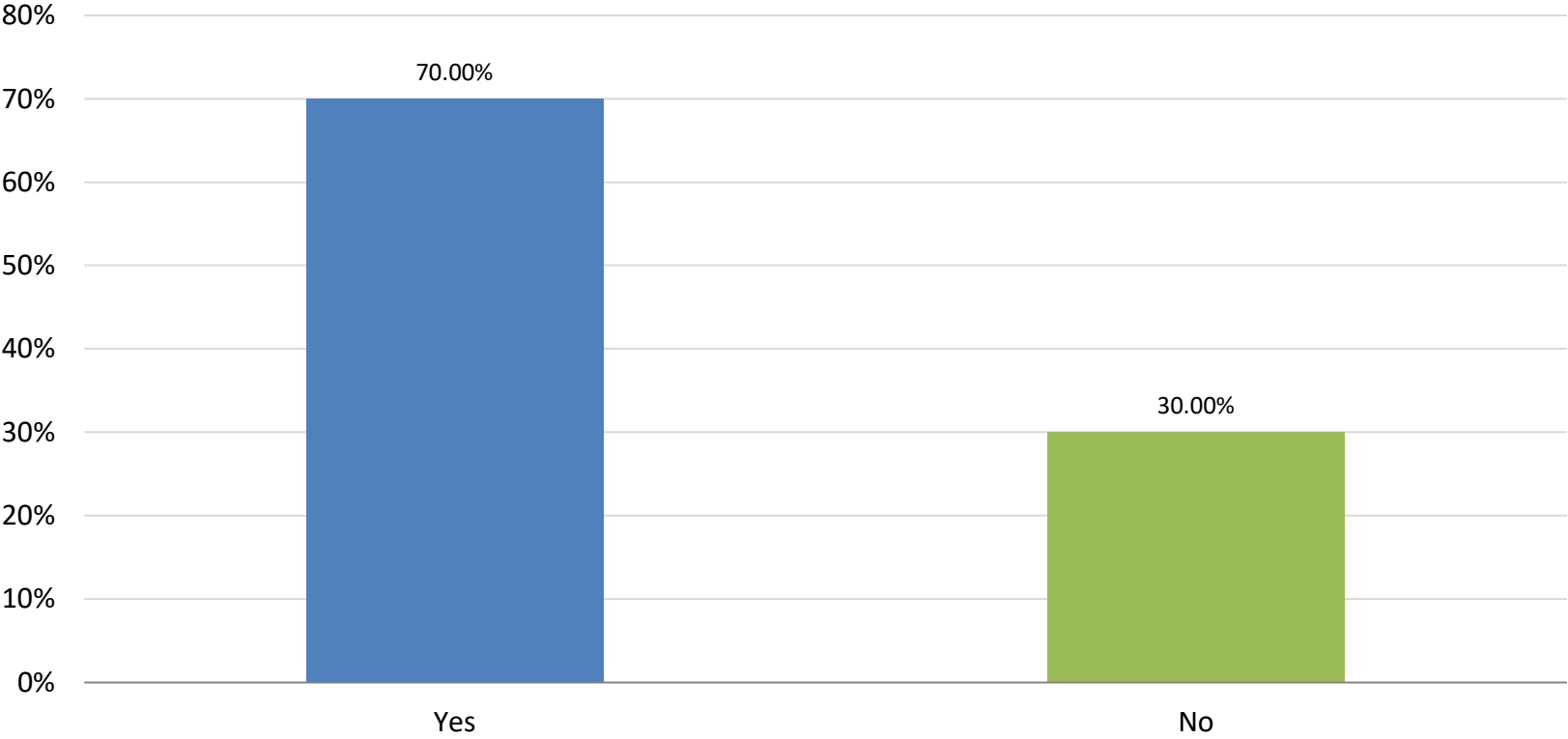
VSI's quarterly newsletters, circulated to our worldwide membership are our primary educational resource and method of outreach. Each edition includes *treatment and medical news updates*, answers to *patient questions* we've received, and *announcements of recruiting clinical trials*.

1 week after circulation, our Spring Edition had been opened over **13,000 times by VSI members in over 100 countries.**

This newsletter included a survey, giving our members the opportunity to tell their vitiligo story, and most importantly to have their voices heard.

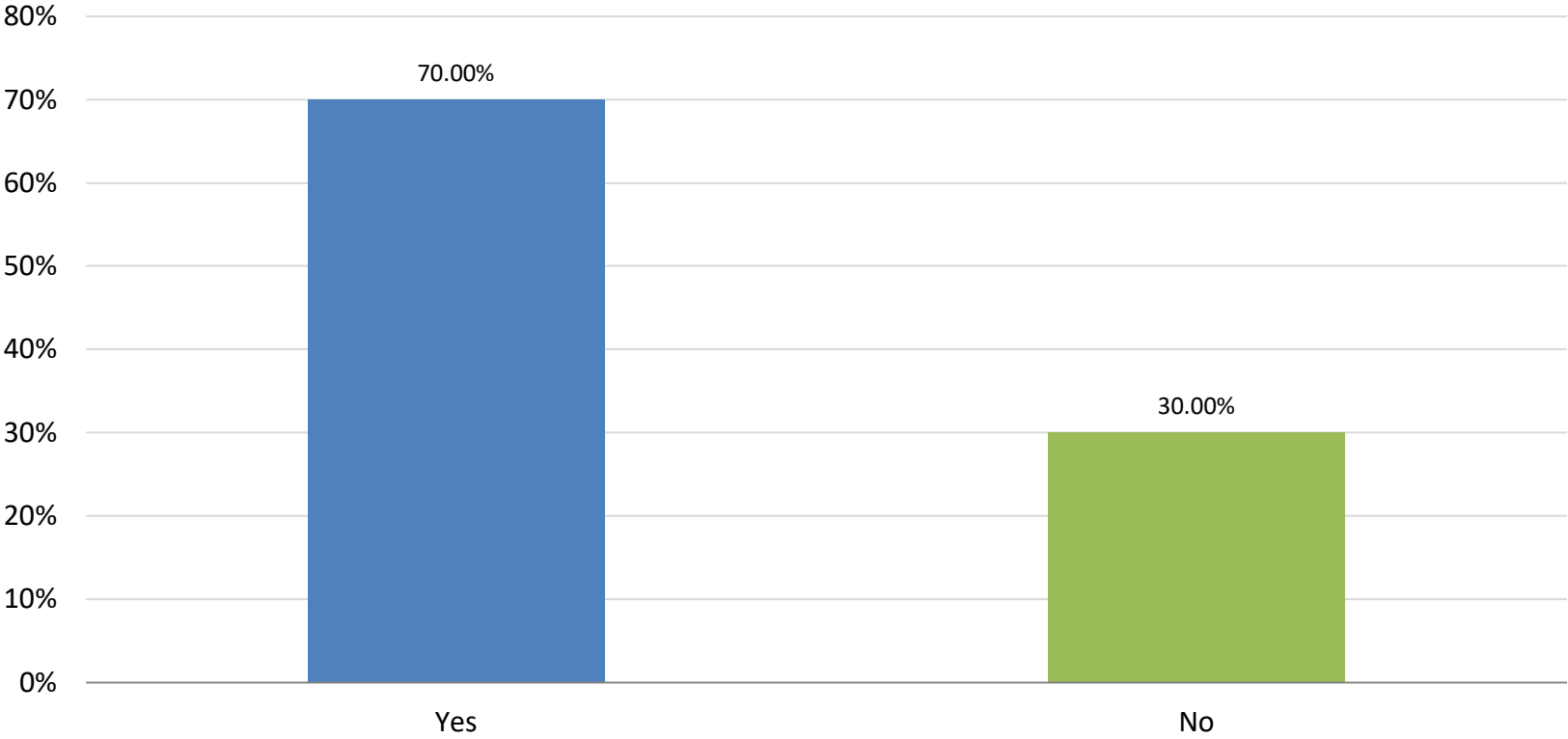
The results we've included here are intended to make perfectly clear – Vitiligo is NOT a Cosmetic Disease.

Have You Ever Felt That if You Didn't Have Vitiligo Your Life Would Have Been Better?



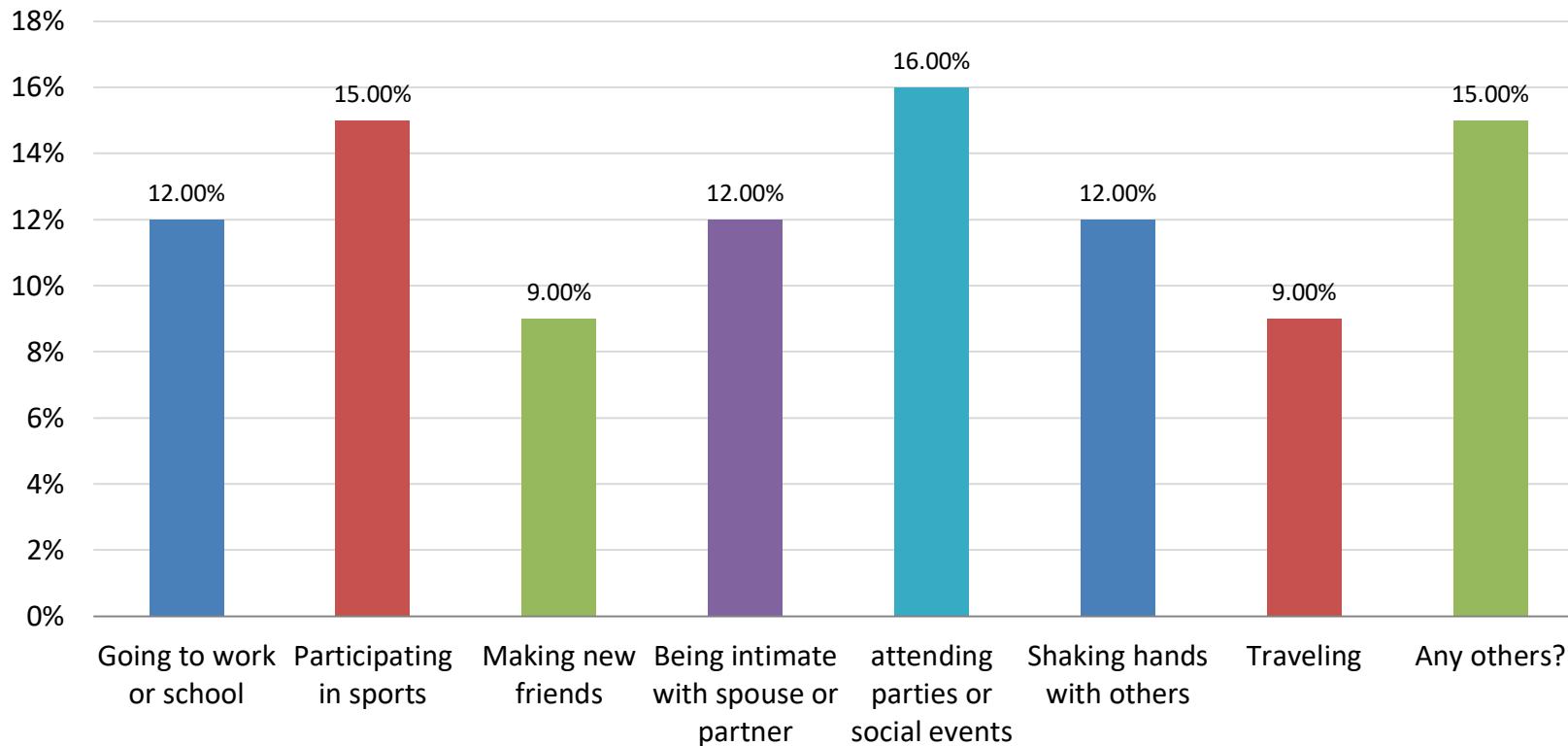
Mean : 1.295 | Confidence Interval @ 95% : [1.159 - 1.432] | Standard Deviation : 0.462 | Standard Error : 0.070

Before You Developed Vitiligo, Did You Participate in More Social Activities?



Mean : 1.302 | Confidence Interval @ 95% : [1.163 - 1.441] | Standard Deviation : 0.465 | Standard Error : 0.071

Select any/all Activities That Have Impacted Your Participation Because of Vitiligo

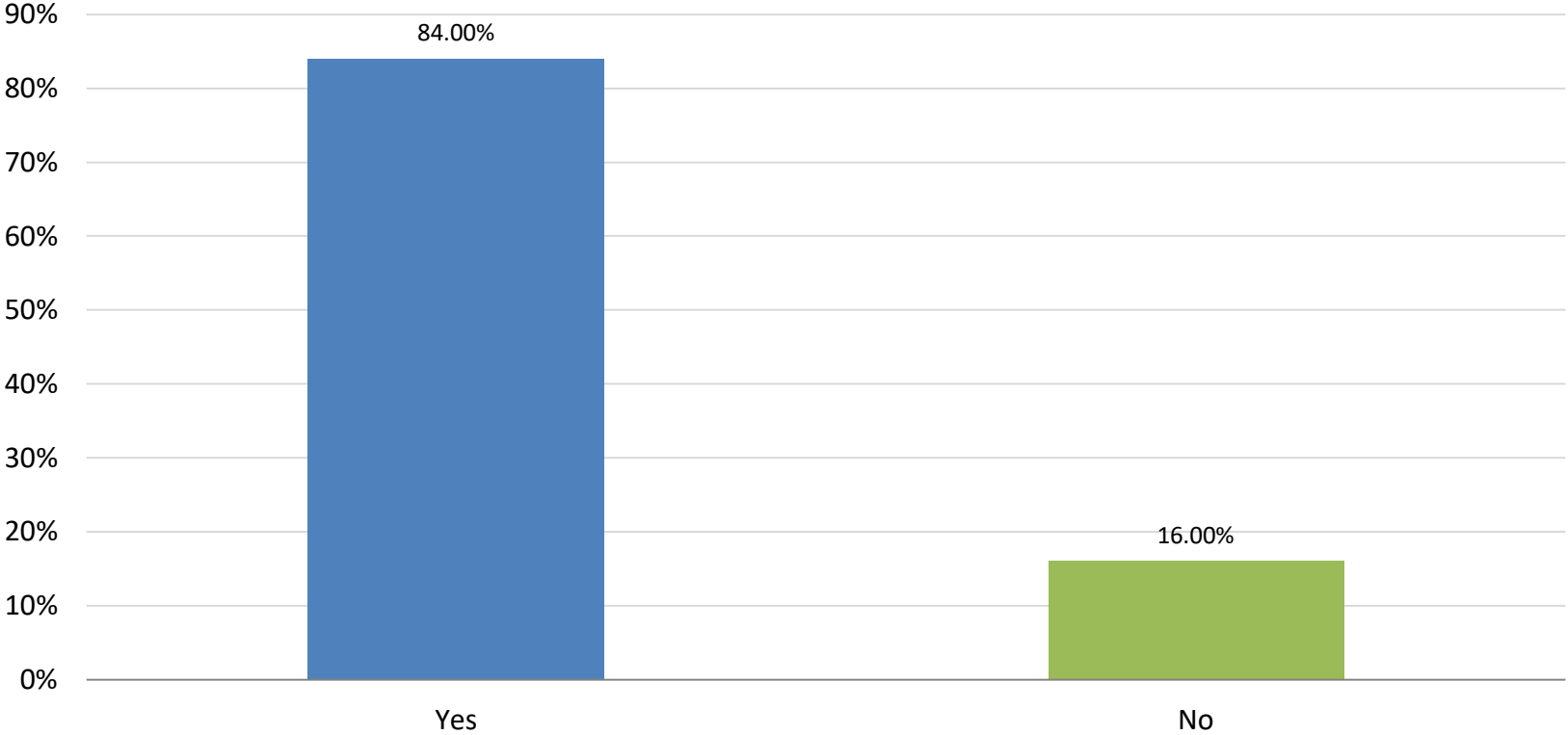


Mean : 4.522 | Confidence Interval @ 95% : [4.046 - 4.997] | Standard Deviation : 2.327 | Standard Error : 0.243

Other Activities Impacted by Vitiligo

- ◆ I no longer attend parties I'm invited to during the summer – because I hate when people stare at me.
- ◆ I avoid going on dating sites from late spring to early fall because I never want to reveal my vitiligo.
- ◆ I will not do a video zoom meeting - not even with family.
- ◆ I no longer post social media pictures.
- ◆ I no longer participate in ANY summer activities.
- ◆ I no longer participate in ANY outdoor activity.
- ◆ I no longer go ANYWHERE in public.
- ◆ I now have social anxiety and wear functional clothing instead of fashionable.
- ◆ I no longer date - so many people see it and don't want to go out with you.
- ◆ I only swim at night, and alone, to avoid looks. And I miss wearing my COVID mask, it made my life so much more comfortable.
- ◆ I will no longer be photographed.

Has Your Vitiligo Ever Made You Feel Sad, Discouraged, or Depressed?



Mean : 1.159 | Confidence Interval @ 95% : [1.050 - 1.268] | Standard Deviation : 0.370 | Standard Error : 0.056

Has Your Vitiligo Ever Made You Feel Sad, Discouraged, or Depressed? Other Comments:

[Yes] But I guess I'm used to being alone most of the time.

[Yes] It's a daily routine to cover up and always in the back of my mind. I'm always concerned about how much worse it will get over time.

[Yes] Watching my entire body change each day, waiting for the spot or disappearance of my pigment.

[Yes] I was more depressed when my daughter developed vitiligo.

[Yes] But I am totally depigmented now, so it's not even about the spots anymore. I've had total strangers ask me why I'm so pale??? I just want pigment. I want a healthy color, especially as I get older.

[Yes] I didn't like children's reaction to my skin as though I was a monster and being afraid of me.

[Yes] On-going feeling of frustration and disappointment

[Yes] But now that I have found effective treatment (in-home NBUVB treatments), I no longer feel so affected by my vitiligo.

Has Your Vitiligo Ever Made You Feel Sad, Discouraged, or Depressed? Other Comments: Cont'd

[Yes] After 50 years I thought I'd finally be OK about having vitiligo on my face. I'm not quite as self-conscious, but every summer it's super depressing to have to dodge the sun and stay in the shade. I still feel like I'm a freak, that I'm not normal and that I am the wet blanket at social gatherings especially if they are outdoors.

[Yes] It really impacted my confidence, especially now returning to dating at my age is daunting enough, but I have found so many people are put off by it, it makes you self-conscious and reluctant to go out.

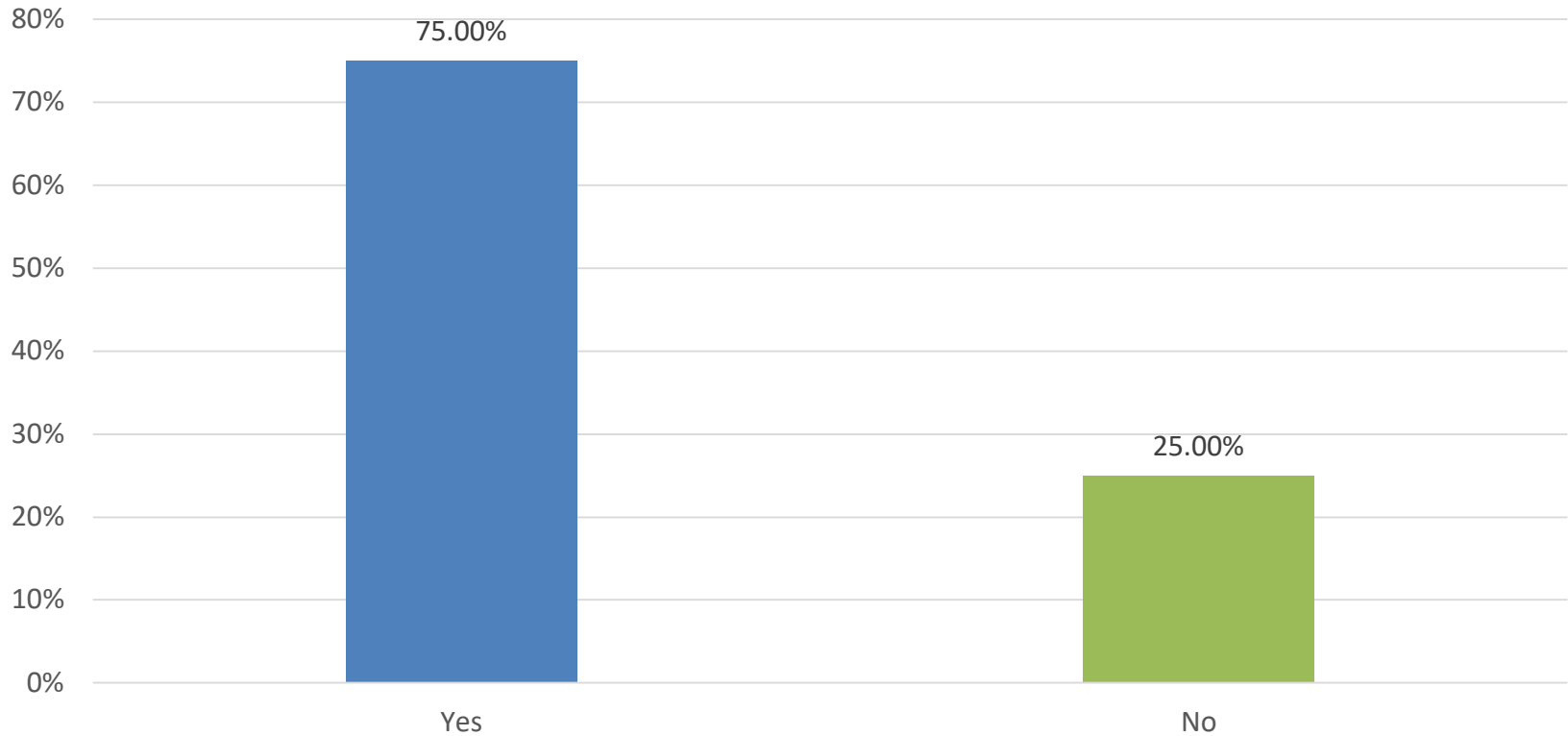
[Yes] Having vitiligo is hard...especially when it also has cultural taboo related with it. Vitiligo affects everyone physically and mentally.

[Yes] My family has always said, **“Oh, we don’t even notice it.” This makes me feel dismissed** because it has been devastating for me to have vitiligo.

[Yes] Vitiligo is a mentally debilitating disease.

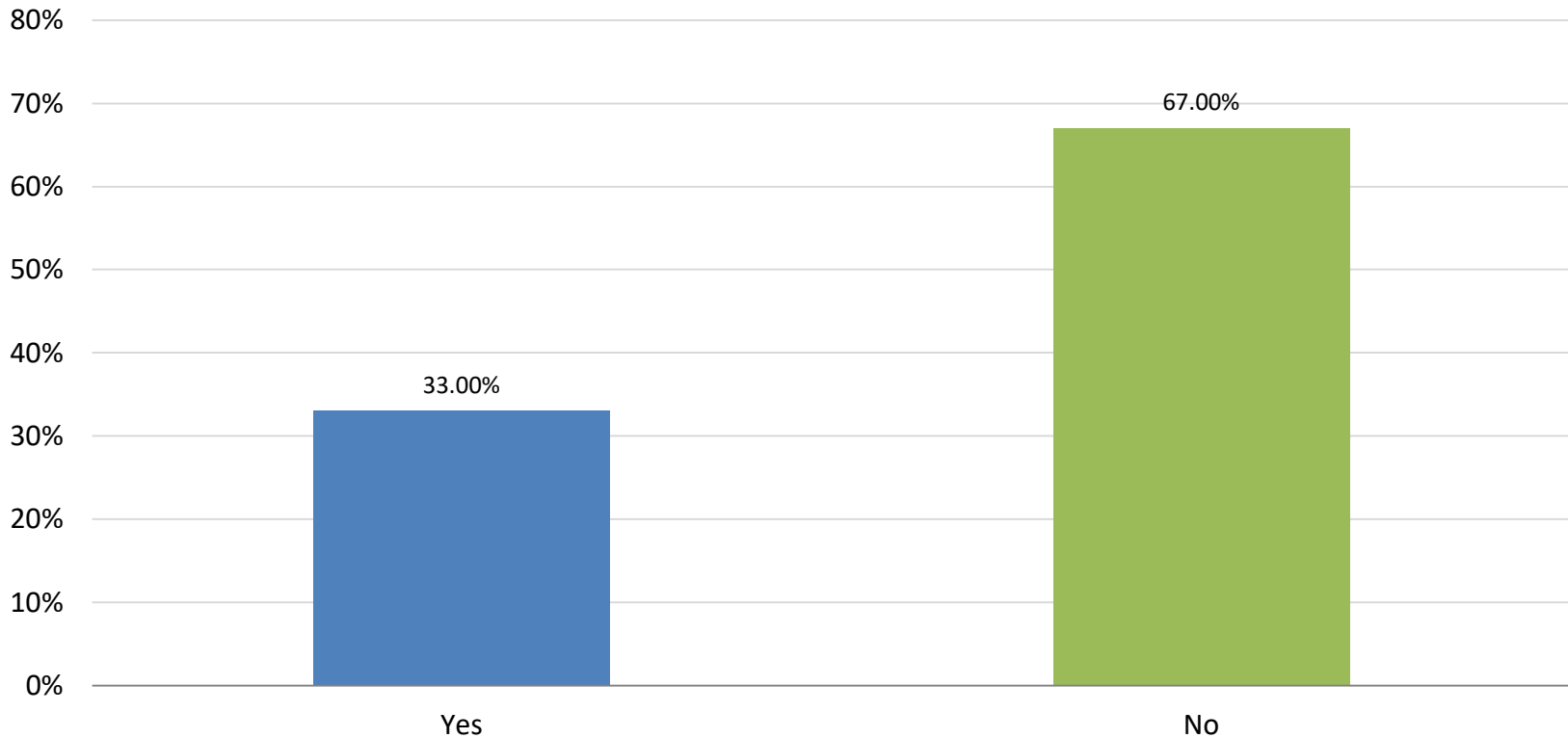
[Yes] Some days your resilience is lower than others, and remarks or looks from people that you would have shrugged off, ruin your mood for the day.

Do You Find Warm Weather More Difficult Because More of Your Vitiligo is Visible?



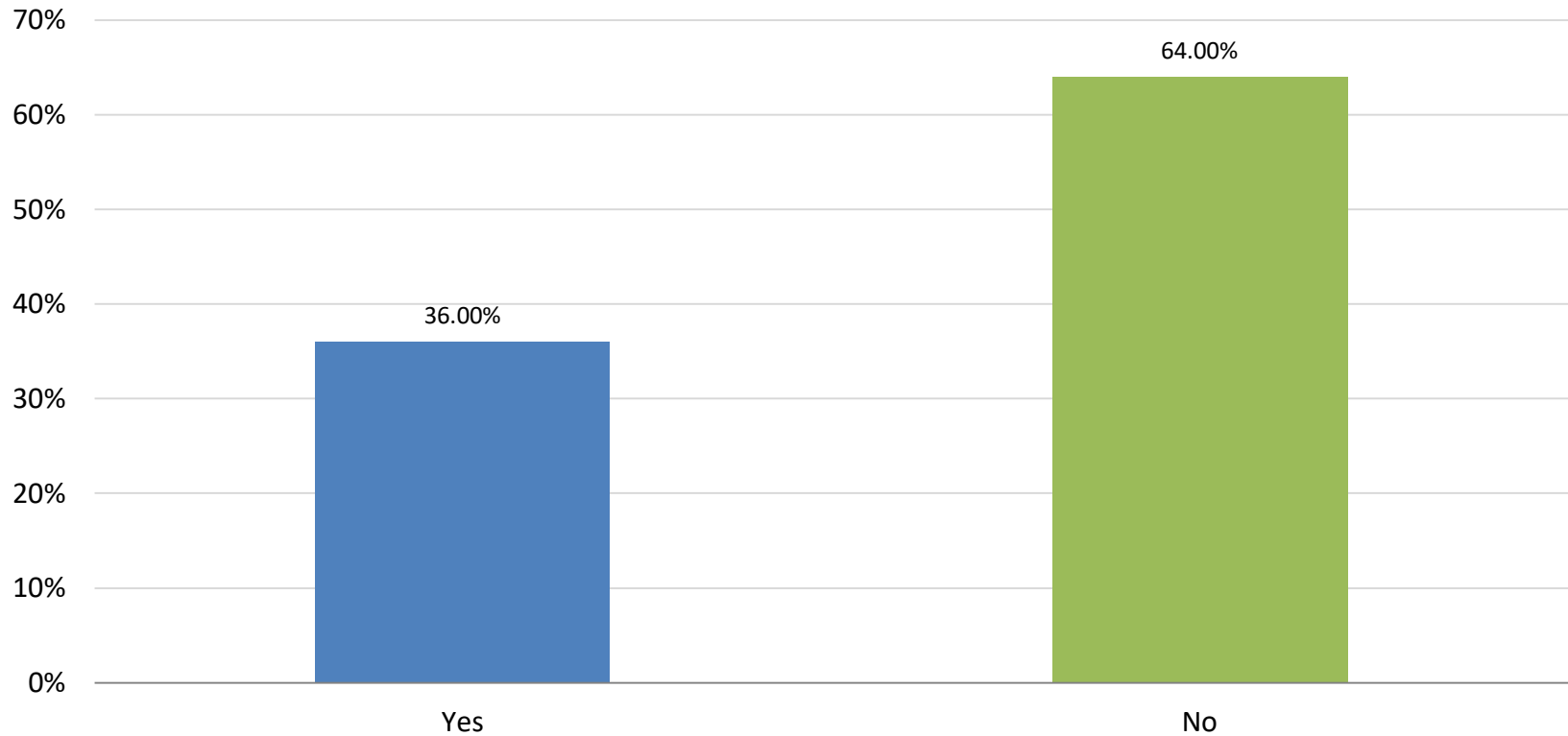
Mean : 1.250 | Confidence Interval @ 95% : [1.121 - 1.379] | Standard Deviation : 0.438 | Standard Error : 0.066

Do You Feel That Your Family Understands How Vitiligo Makes You Feel?



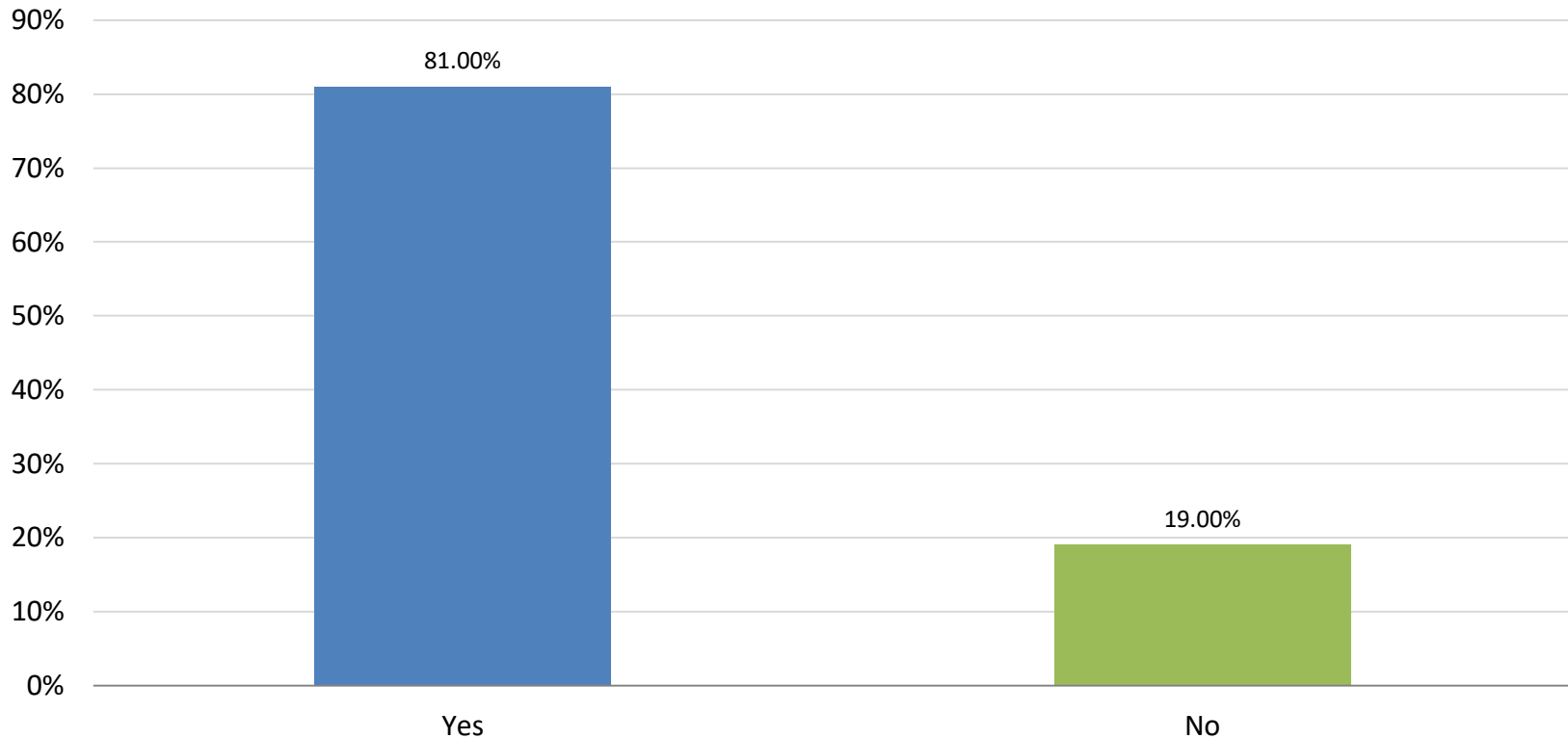
Mean : 1.667 | Confidence Interval @ 95% : [1.522 - 1.811] | Standard Deviation : 0.477 | Standard Error : 0.074

Do You Feel That Your Friends Understand How Vitiligo Makes You Feel?



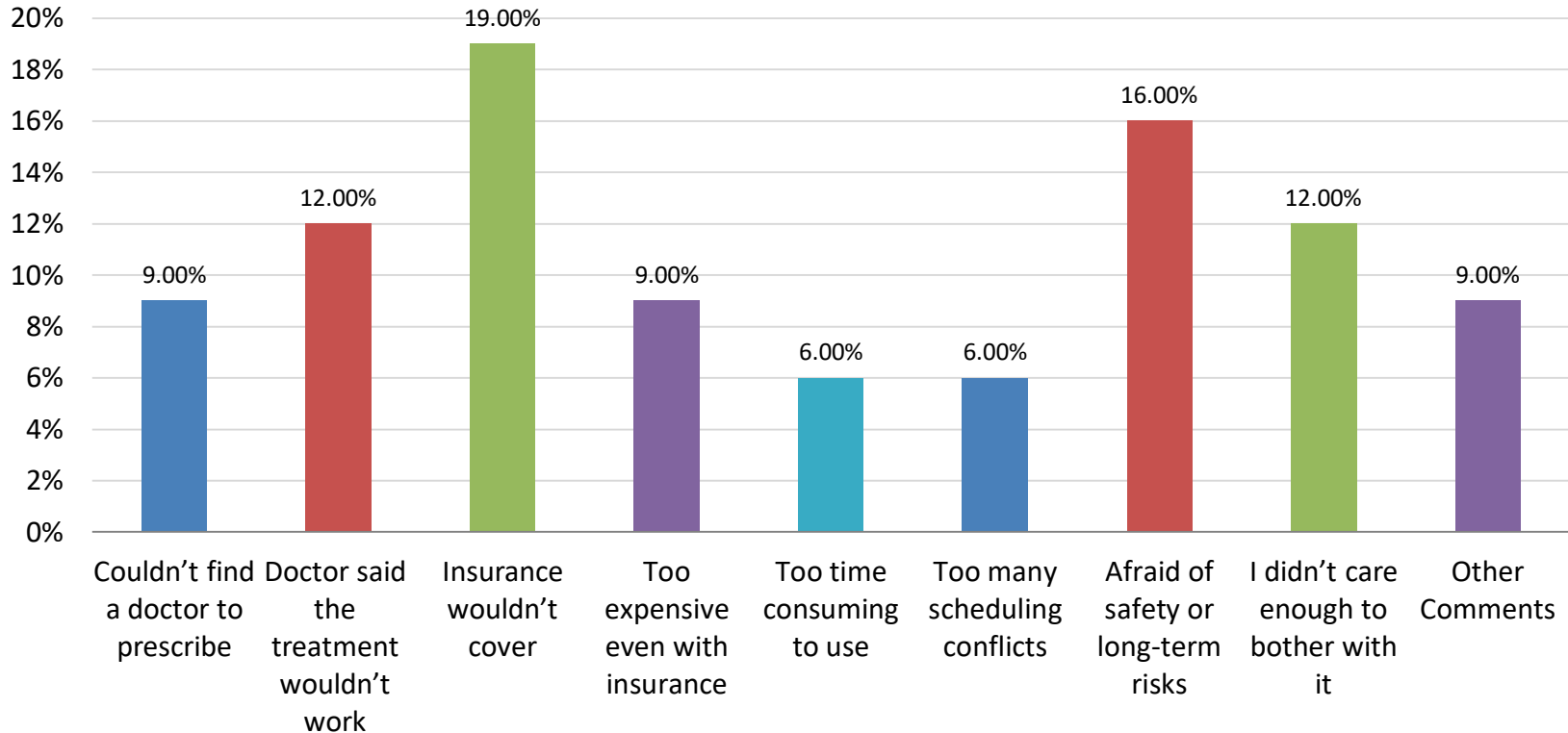
Mean : 1.636 | Confidence Interval @ 95% : [1.493 - 1.780] | Standard Deviation : 0.487 | Standard Error : 0.073

Have You Ever Been Stared at in Public Because of Vitiligo?



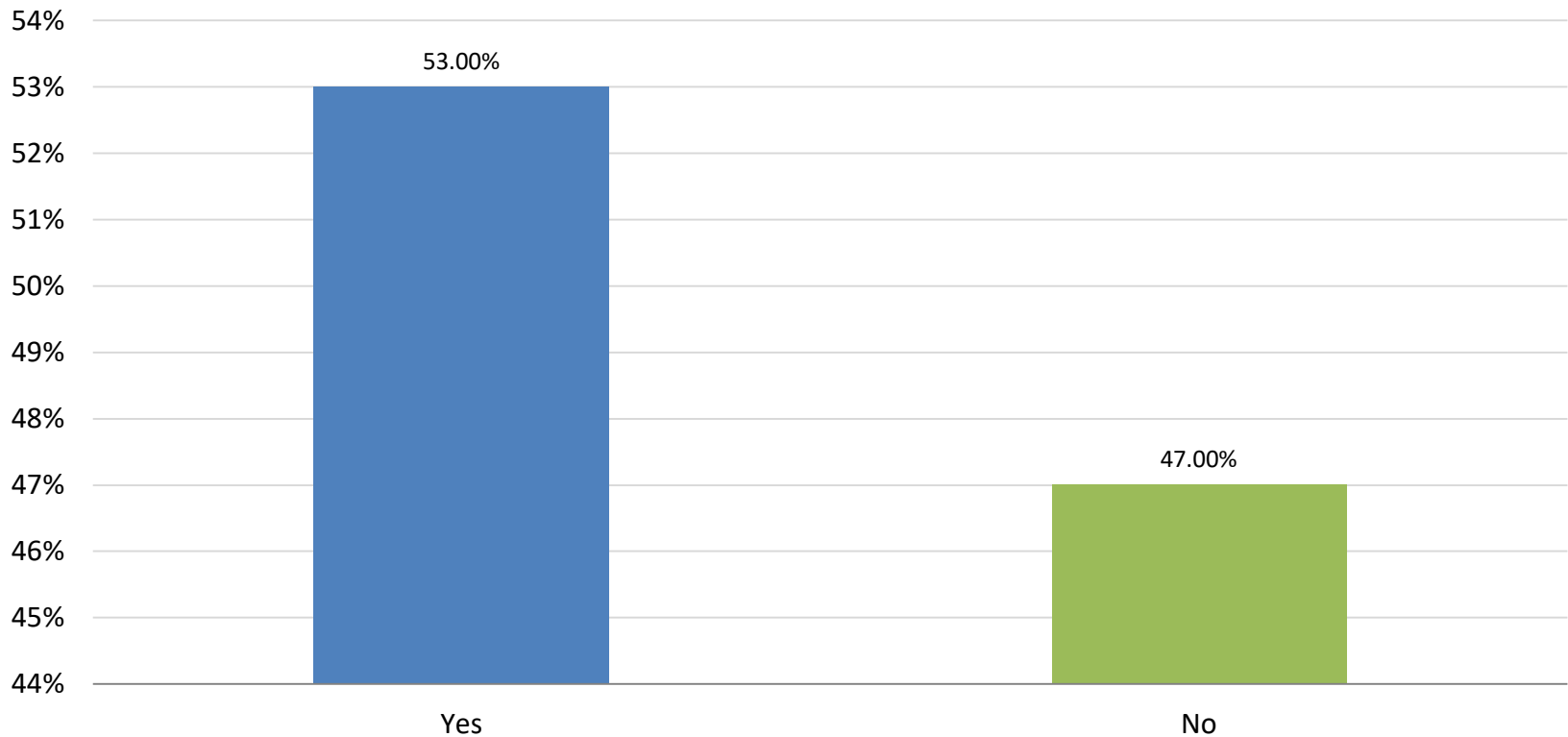
Mean : 1.186 | Confidence Interval @ 95% : [1.068 - 1.304] | Standard Deviation : 0.394 | Standard Error : 0.060

If You NEVER Tried A Medical Treatment, Select All Reasons That Influenced That Decision.



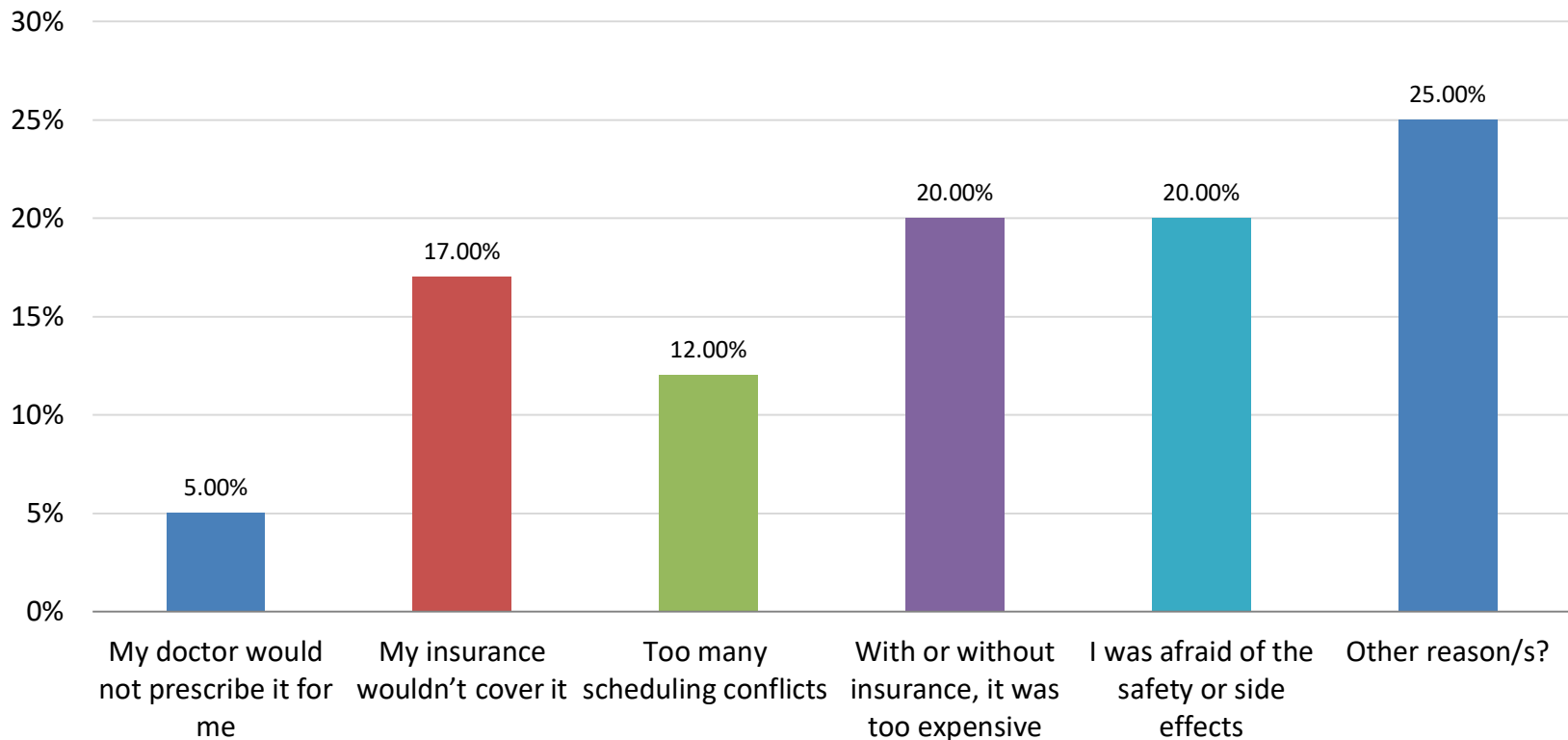
Mean : 4.906 | Confidence Interval @ 95% : [3.990 - 5.822] | Standard Deviation : 2.644 | Standard Error : 0.467

At Any Point in Your Life, Was There a Medical Treatment/s That You WANTED to Try But You Were UNABLE To?



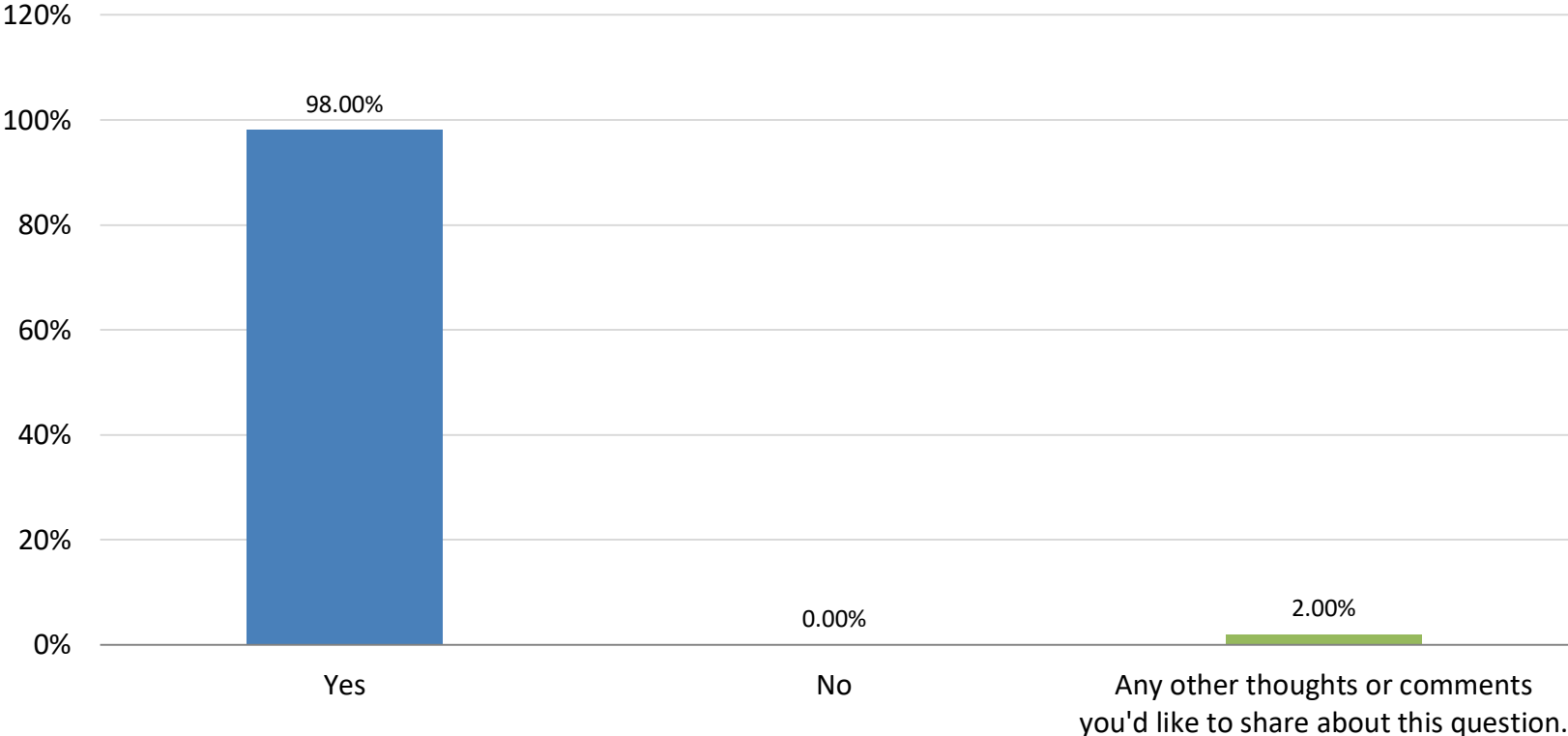
Mean : 1.475 | Confidence Interval @ 95% : [1.318 - 1.632] | Standard Deviation : 0.506 | Standard Error : 0.080

If You DID Want to Try a Medical Treatment But Were UNABLE to, Select All Reasons That Kept You From Trying.



Mean : 4.075 | Confidence Interval @ 95% : [3.582 - 4.568] | Standard Deviation : 1.591 | Standard Error : 0.252

If There Was a Safe Treatment That You Could Afford, That Worked Well, And You Only Had To Use it Once A Week, Would You Consider Trying It?



Mean : 1.048 | Confidence Interval @ 95% : [0.954 - 1.141] | Standard Deviation : 0.309 | Standard Error : 0.048

Is There Anything That You Want the World to Know About Vitiligo?

- ♦ ***Every single patient is different.*** We are not a monolith. It's annoying to be expected to have the same emotional reaction or mindset as everyone else (e.g.: "embrace it" because a famous model has it and is thriving). People take for granted the acceptance they receive based on how they look, with something as basic as skin tone uniformity. Strangers can't help but react in the moment to you, and some are less empathetic than others. Some are outright cruel. There is a great deal of emotional labor, even hidden from myself at times, that goes into meeting each day with confidence, knowing any stranger might make a comment or give a look that is one more rejection I have to process, absorb and move on from.
- ♦ ***That it has a daily impact*** on our lives that is not well understood since it is more emotional than directly life threatening. It's something we have to constantly contend with and the uncertainties of worsening. I am hopeful that a permanent and affordable treatment can be found.
- ♦ ***That it isn't contagious (x 10)***

Is There Anything That You Want the World to Know About Vitiligo? Cont'd ...

- ◆ ***That having vitiligo*** is a life-changing condition that has impacted my life in ways that most people could never understand. It has led to depression, stress, and social anxiety. It has led to poor and stupid decisions. **Thank you for letting me have a voice after all of these years.** I hope that there is adequate funding that someday leads to a cure for this awful skin condition.
- ◆ ***Vitiligo is a heartbreaking plague***...it hurts...it sucks... I have no confidence. It takes me 2 hours of makeup to go anywhere and another removing it all.
- ◆ ***Vitiligo is hard*** physically and mentally and the world needs to be educated about it. Whether we choose to live with it, cover it up, or try treatment, the choices should be supported. Doctors need to keep up on the research and educate themselves as well.
- ◆ ***I want the scientific community*** to stop treating vitiligo solely as a dermatological problem. Vitiligo is the skin manifestation of a broader, systemic problem with emotional causes and/or consequences. I would like the scientific community and the policy makers to prioritize research on treatment approaches addressing the root causes of vitiligo.

Is There Anything That You Want the World to Know About Vitiligo? Cont'd ...

- ◆ ***That vitiligo is a devastating condition.*** As a child, I was always self-conscious. I couldn't swim or be in the sun like everyone else. I still hate wearing shorts sleeves and shorts.
- ◆ ***Even though*** it is not a disease that people can contract, you feel like a pariah.
- ◆ ***I just want*** doctors to fully understand the options. **I want them to tell me about VSI instead of me finding it 7 years into my diagnosis.** I want scientists to find a treatment!
- ◆ ***That it may not*** impact your health or cause pain the way many other diseases do, but it is psychologically debilitating and kills your spirit, enthusiasm and joy for living. Most people have no idea what it feels like. I thank the very few doctors, researchers, and pharmaceutical companies that are brave enough to spend their time researching for good treatments and a cure for those of us that suffer from vitiligo.
- ◆ ***That we are peoples*** like everyone.
- ◆ ***That just because it is not physically painful does not mean it doesn't hurt.***



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Please Support this Important Work

From national advocacy to personal patient support, VSI continues to represent the voice of the patient, providing trusted and reliable resources to the vitiligo community.

As a 501(c)(3) nonprofit organization, VSI is dependent on public funding to provide these services.

Together We Can Make a Difference

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