

Evaluating Population Interest in Vitiligo Through an Analysis of Google Trends and Social Media

Simone Nicole Boeckmann Montgomery BA and Nada Elbuluk MD MSc

Department of Dermatology, Keck School of Medicine at the University of Southern California, Los Angeles, CA

INTRODUCTION

Vitiligo is an autoimmune pigmentary condition with a complex, multifactorial pathogenesis resulting in depigmentation of skin. It affects between 0.4-2% of the population worldwide.¹ In recent years, vitiligo has seen a significant increase in attention in both mainstream media and on social media. Prior to the emergence of body positivity campaigns and supermodel Winnie Harlow, representation of vitiligo in the media was sparse, focusing mostly on the skin lightening transformation of artists like Michael Jackson and Sinbad. In contrast, today, there are numerous advertising campaigns and platforms from makeup and clothing companies to patient-organized support groups encouraging representation of vitiligo and positive awareness about the condition.

Nearly 90% of Americans use the internet, which has transformed the way information is provided and accessed.² The domain of health-related information is no exception. More than 72% of Americans report having used the internet for health-related questions, including exploring the potential diagnosis for symptoms, a diagnosis given to them, disease progression information, and symptom management.³ Furthermore, it has been reported that the internet, has become the first, and sometimes only, source of health information for patients.⁴ Google holds 88.5% of the market share of search engines, with over 3.5 billion daily queries – 7% of which are reported to be health-related.^{5,6}

Google Trends is a search tool which tracks and reports the search volume of a specific query over time and/or within a specific region. Recognizing the power of having access to the over 3.5 billion daily queries, the field of medicine has begun to adopt Google Trends and the use of big data as a powerful epidemiological tool to track population trends and interests over time. In dermatology, studies using Google Trends have been used to elucidate population interest in several conditions including skin cancer, psoriasis, and Botox.^{7,8,9} In addition to patients' using Google to obtain background information and explore health issues on various websites, social media has also evolved from a personal sharing space to a marketplace of information, services, and products. Instagram, a photo-sharing app, has become the most popular social media platform, serving over 110 million users in the United States and over 800

million users worldwide.¹⁰ Indeed in 2018, forty-two percent of Americans reported use of social media platforms, such as Instagram, to search for health-related information.¹¹

Vitiligo has seen a significant increase in attention in mainstream media, ranging from campaigns to 'embrace the skin you are in' to supermodels with vitiligo being featured as the face of major retailers. To date there has been only one peer-reviewed study using Google Trends to examine interest in vitiligo. However, our study is the first to use both Google Trends and a social media platform to elucidate public knowledge patterns about vitiligo and general interest in vitiligo. The goal of this study is to 1) apply Google Trends to track and elucidate the temporal and geographical trends, related interests, and top searches about vitiligo and 2) to summarize the content of vitiligo related treatments and topics on Instagram and document its growing presence.

METHODS

The keyword of vitiligo was entered (August 15, 2019) in Google search and we recorded the number of results and the content of the top page of results. Next, Google Trends was used to explore temporal and geographical population interest related to vitiligo. Searches were limited to those performed in the United States from January 1, 2004, the earliest year with recorded Google Trends data, through December 31, 2018. Google Trends presents temporal and geographical trends as relative search volumes (RSV) on a scale of 1-100, which allows for normalization of geographic and population sizes. Interest over time (temporal) was recorded as RSV per month, and subsequently, annual RSV was estimated by calculating the mean of each monthly RSV per year. Interest by subregion was also recorded as RSV for each state. The subcategory of "Related Queries" was then explored. This subcategory is also provided in the Google Trends analysis and identifies the most frequent subsequent searches by users who initially searched for vitiligo.

We also searched the keyword of vitiligo as a hashtag on Instagram and recorded the number of total posts, with Instagram providing a "Top Posts" page with a continuous list of images. A sample of 300 top posts were recorded and categorized based on content and source (Figure 1a and 1b).

FIGURE 1A. Image content of top related posts on Instagram in 2019.

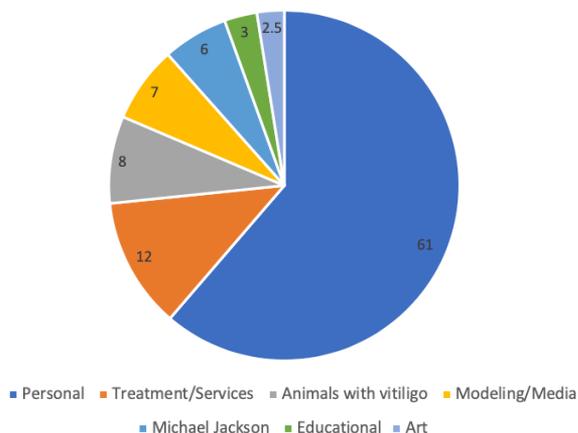


FIGURE 1B. Image sources of top related posts on Instagram in 2019.

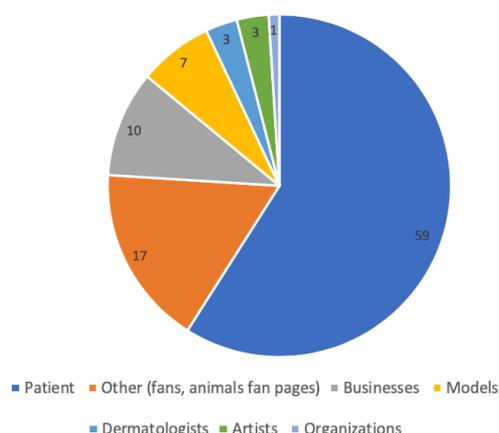


FIGURE 2A. Monthly residual search volume in vitiligo.

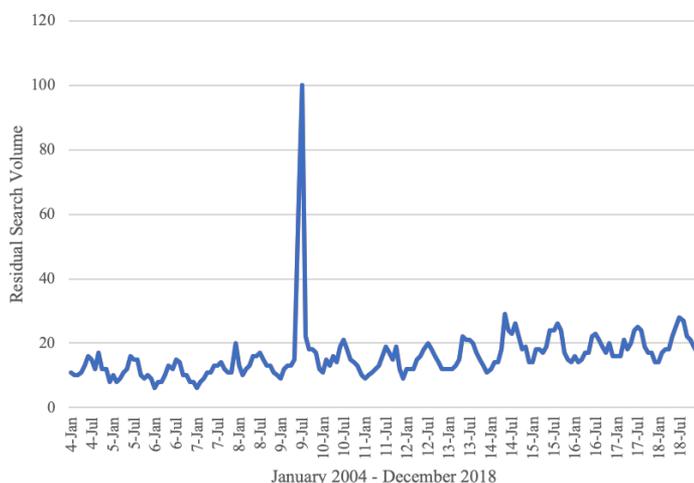
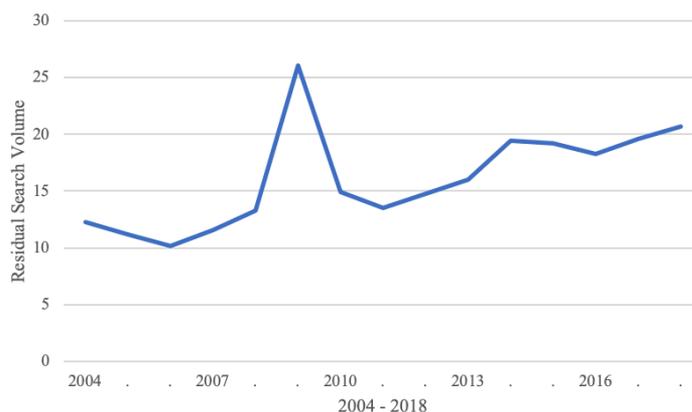


FIGURE 2B. Annual residual search volume in vitiligo.

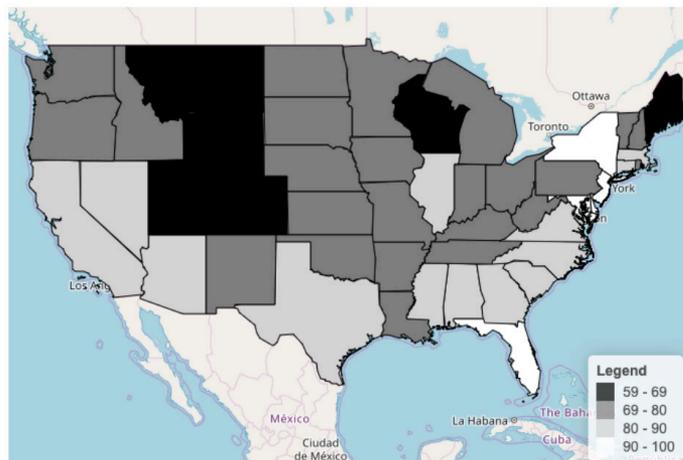


RESULTS

The initial Google search using the term vitiligo yielded over 20,000,000 results. The top page of results included information pages from Mayo Clinic, American Academy of Dermatology (AAD), Web MD, Medline Plus, and NIH. Links to top news stories, top images, and top alternative searches were also included.

The RSVs for the term vitiligo for each month from January 1, 2004 through December 31, 2018 ranged from 6 to 100, while estimated annual RSVs ranged from 10 to 20. Both monthly and annual RSVs are trended and presented in Figures 2a and 2b. In 2009, the annual RSV increased to 26 from 13, equating to a 100% increase in searches, before returning to the low teens for the following three years. This increase in annual estimated RSV is significantly impacted by the monthly RSVs for May and June in 2009, recorded at 64 and 100, respectively. Geographic distribution of searches for the keyword vitiligo revealed high-

FIGURE 3. Heat Map of Continental United States. This heat map displays the relative search volume by state, controlled for population size. A relative search volume of 100 is assigned to states with the highest proportions of searches.



Top Queries and Rising Related Queries on Google Trends. Top queries and rising related top queries are searches with the biggest increase in search frequency in the defined time-period (i.e. over 1 year). Search frequency is measured by growth percent. "Breakout" is defined as more than 5000% growth compared to previous year.

Year	Top Queries	RSV	Top Rising Related Queries	Growth %
2005	vitiligo treatment	100	vitiligo treatment	90% ↑
	vitiligo support	37		
2006	vitiligo treatment	100	vitiligo cure	300% ↑
	vitiligo cure	79	vitaligo	80% ↑
	vitiligo support	50		
	vitaligo	36		
2007	vitiligo treatment	100	National Vitiligo Foundation	Breakout
	vitiligo pictures	72	Lee Thomas	Breakout
	white spots on skin	39	skin discoloration	100% ↑
	vitiligo support	39	vitiligo treatment	70% ↑
	tinea versicolor	36	vitiligo pictures	50% ↑
2008	vitiligo Michael Jackson	100	vitiligo Michael Jackson	250% ↑
	Michael Jackson	92	vitiligo symptoms	180% ↑
	vitiligo treatment	89	what is vitiligo	170% ↑
	what is vitiligo	52	Michael Jackson	140% ↑
	vitiligo symptoms	41	Protopic	80% ↑
2009	Michael Jackson	100	Michael Jackson vitiligo pictures	Breakout
	vitiligo Michael Jackson	98	did Michael Jackson have vitiligo	Breakout
	vitiligo skin	68	vitiligo symptoms	Breakout
	vitiligo pictures	41	vitiligo more condition symptoms	Breakout
	vitiligo treatment	36	que es vitiligo	Breakout
2010	vitiligo treatment	100	Prince Jackson vitiligo	130% ↑
	vitiligo pictures	67	vitiligo treatment	90% ↑
	Michael Jackson	65	vitiligo cure	90% ↑
	vitiligo Michael Jackson	57	Prince Michael Jackson vitiligo	80% ↑
	vitiligo disease	47	causes of vitiligo	80% ↑
2011	vitiligo treatment	100	vitiligo treatment 2011	Breakout
	vitiligo pictures	67	vital	Breakout
	vitiligo Michael Jackson	58	hypothyroidism	Breakout
	Michael Jackson	53	is vitiligo hereditary	Breakout
	vitiligo disease	40	Vitality	Breakout
2012	vitiligo treatment	100	cura para el vitiligo	Breakout
	vitiligo Michael Jackson	60	Tempestt Bledsoe	Breakout
	Michael Jackson	60	is vitiligo hereditary	170% ↑
	vitiligo cure	57	que es vitiligo	160% ↑
	vitiligo disease	55	vitiligo photos	140% ↑
2013	vitiligo treatment	100	Katherine Webb	Breakout
	vitiligo cure	91	Joe Rogan vitiligo	Breakout
	vitiligo Michael Jackson	90	vitiligo treatment 2013	Breakout
	Michael Jackson	78	vitiligo meaning	Breakout
	vitiligo disease	64	AJ McCarron	Breakout
2014	vitiligo skin	100	Chantelle Brown-Young	Breakout
	vitiligo Michael Jackson	48	Winnie Harlow	Breakout
	Michael Jackson	47	ANTM vitiligo	Breakout
	vitiligo cure	45	vitiligo cure 2014	Breakout
	vitiligo treatment	43	Top Model vitiligo	Breakout
2015	vitiligo skin	100	vitiligo treatment 2015	Breakout
	vitiligo Michael Jackson	40	vitiligo cure 2015	Breakout
	Michael Jackson	39	Michael Jackson vitiligo 1986	Breakout
	vitiligo treatment	37	Tacrolimus ointment	Breakout
	vitiligo model	34	Modelo con vitiligo	4,550% ↑
2016	vitiligo skin	100	vitiligo treatment 2016	Breakout
	vitiligo model	40	is vitiligo genetic	Breakout
	vitiligo Michael Jackson	40	Michael Jackson vitiligo Oprah	Breakout
	Michael Jackson	36	Autoimmune disorder	Breakout
	vitiligo cure	35	vitiligo cure 2016	Breakout
2017	vitiligo skin	100	vitiligo treatment 2017	Breakout
	Michael Jackson	39	vitiligo cure 2017	Breakout
	vitiligo Michael Jackson	38	Michael Jackson vitiligo	Breakout
	what is vitiligo	30	Michael Jackson vitiligo no makeup	Breakout
	vitiligo disease	30	Michael Jackson skin disease youtube	Breakout
2018	vitiligo skin	100	vitiligo treatment 2018	breakout
	Michael Jackson	42	vitiligo cure 2018	breakout
	vitiligo Michael Jackson	41	does vitiligo hurt	breakout

est interest in New Jersey, New York, Florida, Maryland, and Delaware, with 45 out of the 50 states having an RSV greater than 70 (Figure 3).

Related queries to the keyword vitiligo are presented in Figure 4, with the most popular searches being “vitiligo skin,” “Michael Jackson/Michael Jackson vitiligo,” and “vitiligo treatment.” Top rising queries included “what is vitiligo,” “vitiligo model/Winnie Harlow,” and “treatment for vitiligo” as the search phrases that are most rapidly increasing in search frequency. The five top related queries and five top rising related queries, defined as searches with the biggest increase in search frequency in the defined time-period, for each individual year from 2005-2018 were recorded. (Table 1) Related queries for year 2004 were not available. “Vitiligo treatment” and “Michael Jackson/vitiligo Michael Jackson” were included in the top five related queries for 11/14 years of available data; “vitiligo cure” was the next most common, appearing in the top five related queries for 5/14.

A search of the hashtag “#Vitiligo” on Instagram revealed over 350,000 vitiligo-related posts. Figure 1 displays a breakdown of the content and sources of the top 300 posts. 61% of posts contained personal content posted by people living with vitiligo, many of which encouraged embracing diversity and loving the skin you are in. 12% of the content of posts advertised treatments and services available to patients with vitiligo, including light treatment, vitiligo cures, make-up and associated tutorials to either celebrate or cover spots, and skin tattooing to cover spots. Only 3% of post content provided educational information about the pathophysiology and disease progression of vitiligo. A mere 1% of posts came from organizations promoting vitiligo awareness, the two most common of which were Vitiligo Society and Unite for Vitiligo. Furthermore, only 3% of posts came from a dermatologist.

DISCUSSION

Aligned with published studies on other dermatologic conditions, we found that both Google Trends and social media platforms provided insights into population interests about vitiligo. Google Trends provided us the ability to analyze big data to investigate population interests over time and, with the rising related queries feature, a means of predicting future trends. Social media platforms, like Instagram, on the other hand, allowed us to explore a more individualized perspective about how issues related to vitiligo are shared among on-line communities.

The Google Trends analysis of the search keyword vitiligo revealed that the number of web searches for vitiligo over time has remained relatively stable with a seasonal sine pattern for web searches, with high RSVs seen during summer months and lower RSVs in winter months. This is not surprising as a condition characterized by depigmentation for most will be more noticeable during the summer months, as darker tans provide greater contrast to the affected areas.

FIGURE 4. Top Vitiligo Queries Word Cloud (2005-2018)



It is also important to note the significant impact celebrities have on perceptions of vitiligo. The RSVs for vitiligo for the months of May and June in 2009 were 64 and 100, respectively. Undoubtedly, the death of Michael Jackson directly contributed to this surge of interest in vitiligo. An analysis of the top rising related queries for the year of 2009 revealed breakout growths, defined as a >5,000% increase, for queries such as “Michael Jackson vitiligo pictures” and “did Michael Jackson have vitiligo.”¹ A smaller but still significant increase in searches occurred in the summer of 2014, with the emergence of Chantelle Brown-Young, better known as supermodel Winnie Harlow, on the television show America’s Next Top Model. Winnie Harlow captured America’s interest with her unique beauty and confidence despite her history of being bullied for vitiligo, sparking numerous diversity and inclusion campaigns centered on embracing one’s skin. Since her breakout in the fashion industry, vitiligo has received an abundance of positive media attention, generating a significant and steadily increasing RSV for vitiligo since that year. Because of positive media coverage and vitiligo champions like Winnie Harlow, there has been a significant push for self-acceptance and embracing the beauty of skin diversity.

While the search “vitiligo treatment” is consistently a top related query, treatment options have only been featured once. Specifically, tacrolimus ointment was featured as a breakout rising related query in 2015. The paucity of treatment-specific searches may represent a lack of widespread discussion about medications for vitiligo but may also reflect the shortage of new treatment options for the condition. With clinical trials now focusing on use of immunosuppressant medications as treatments for vitiligo, the rising related query feature of Google Trends may be an effective tool in tracking the use and perceived value of these new treatment options.

The main limitation of examining Google Trends to explore the internet presence of vitiligo is inherently linked to its usefulness; it can only provide population-level analyses of trends and interest and disregards individual variation. However, when

supplemented with analysis of social media – in this case Instagram – we were able to perform a more complete evaluation of population trends as well as how interest in and knowledge of vitiligo is being shared. The content of the top 300 Instagram posts consisted of 61% personal images posted by patients with vitiligo, many of which included captions encouraging others to embrace diversity. Almost all the consistent top posters referred to themselves in their account bios as vitiligo ambassadors or advocates, dedicated to spreading awareness about the condition and increasing representation in the media. A mere 3% of posts were posted by dermatologists, only one of whom was a board-certified dermatologist in the United States. Considering that forty-two percent of Americans report using social media to search for health-related information, there is significant opportunity for dermatologists to take advantage of this market to raise awareness and provide educational information about vitiligo.

Despite the seemingly unified movement in mainstream media and on social media to educate and increase representation of vitiligo positivity, it is important to remember that though many patients have embraced their skin and are proud of their uniqueness, there are many who are still searching for new treatment options, struggling with self- and peer-acceptance, and experiencing discrimination. As the impact of the internet and social media continue to grow in scope, it is imperative that physicians learn to actively engage in the technology and consider inclusive approaches to using these larger platforms to encourage self-acceptance while also continuing to educate and promote emerging treatment options. With the entirety of the internet and social media at their fingertips, patients are taking a more active role in their health, but most do so without sufficient backgrounds to understand the complexities of issues involved. Understanding how patients are using these platforms and acquiring information will allow physicians to better understand and serve their patients. Thus, it is imperative that health professionals recognize the growing role of the internet and social media and actively engage in the technology to help guide their patients as they navigate online health-related information. Additionally, the ability of physicians to provide relevant, reliable online and social media sources is an opportunity to strengthen the patient-physician relationship.

DISCLOSURE

The authors have no conflicts.

REFERENCES

- Alkhateeb A, et al. Epidemiology of vitiligo and associated autoimmune diseases in Caucasian probands and their families. *Pigment Cell Res*. 2003. 16(3):208-14.
- Internet/Broadband Fact Sheet. Internet and Technology, Pew Research Center, 2019. Available from: < <https://www.pewinternet.org/fact-sheet/internet-broadband/> >. Accessed on: September 29.
- Asch JM, et al. Google search histories of patients presenting to an emergency department: an observational study. *BMJ Open*. 2019. 9(22):e024791.
- Cocco AM, et al. Dr Google in the ED: searching for online health information by adult emergency department patients. *Med J Aust*. 2018. 209(8):342-347. Available from: < <https://www.ncbi.nlm.nih.gov/pubmed/30107763> >.
- Clement J. Worldwide desktop market share of leading search engines from January 2010 to July 2019. Statista. 2019. Available from: < <https://www.statista.com/statistics/216573/worldwide-market-share-of-search-engines/> >. Accessed on September 27.
- Drees J. Google receives more than 1 billion health questions every day: Becker's 2019.
- Seidl S, et al. What do Germans want to know about skin cancer? A nationwide Google search analysis from 2013 to 2017. *J Med Internet Res*. 2018. 20(5):e10327.
- Martinez-Lopez A, Ruiz-Villaverde R, Molina-Leyva A. Google search trends in psoriasis: A pilot evaluation of global population interests. *J Eur Acad Dermatol Venereol*. 2018. 32(10):
- Motosko CC, et al. Googling aesthetic plastic surgery for patient insights into the latest trends. *Plast Reconstr Surg*. 2018. 142(6):1478-1485.
- Clement J. Number of monthly active Instagram users from January 2013-2018 (in millions). Statista, 2019. Available from: < <https://www.statista.com/statistics/253577/number-of-monthly-active-instagram-users/> >. Accessed on September 27.
- Park JH, et al. Dermatology on Instagram: An analysis of hashtags. *J Drugs Dermatol*. 2018. 17:482-484.

AUTHOR CORRESPONDENCE

Simone Nicole Boeckmann Montgomery

E-mail:..... snmontgo@usc.edu