

SUPPLEMENTARY MATERIAL

Assessing Participants' Experiences With Vitiligo From Qualitative Interviews

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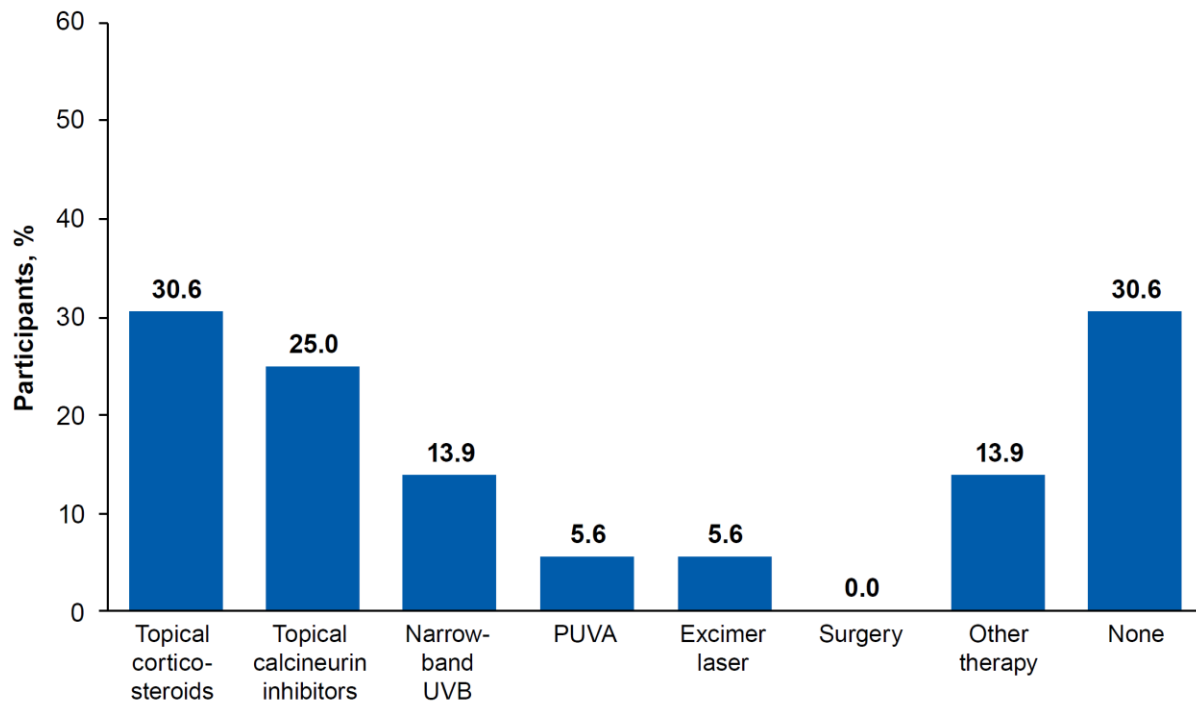
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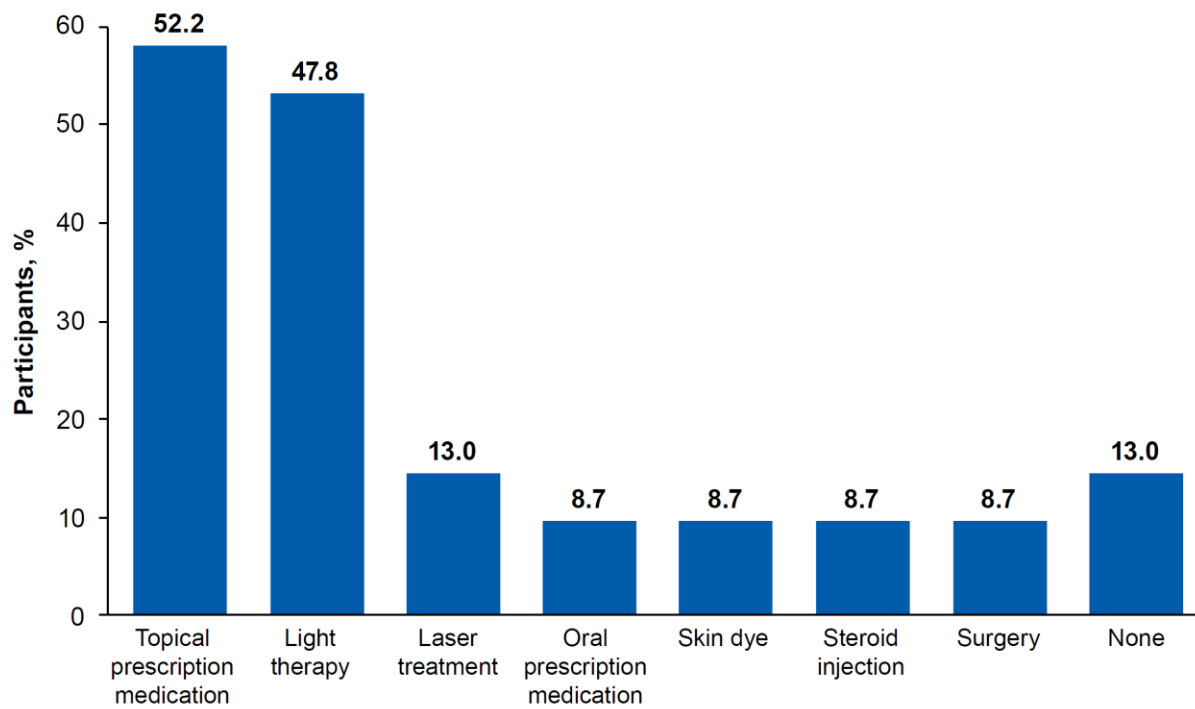
Figure S1. Prior Vitiligo Treatments Among Study 1 Participants^a



PUVA, psoralen plus ultraviolet A; UVB, ultraviolet B.

^a Participants could receive >1 prior treatment.

Figure S2. Prior Vitiligo Treatments Among Study 2 Participants^a



^a Participants could receive >1 prior treatment.

Appendix S1. Study 1: Vitiligo Sub-Study Patient Interviews: Discussion Guide

Vitiligo Sub-Study Patient Interviews

-- Discussion Guide --

I. Introduction (5 minutes)

Hello,

This is [*Interviewer Name*] from IQVIA calling to speak to [*Patient Name*]. Thank you for your interest and for consenting (agreeing) to participate in this research interview. We appreciate you taking time out of your day to speak with us.

Do you have any questions about the study or the Consent Addendum (the form you signed in which you provided written agreement to participate)?

As a reminder, the purpose of this interview study is to talk about your experience with vitiligo and how it has affected your life.

IQVIA is conducting this 60-minute interview on behalf of Incyte Corporation. Through the consent addendum that you've already read and signed, you've been informed about what personal information will be collected from you and how it will be used, shared, processed, transferred and stored. The consent addendum has also informed you about your rights over your personal information. As a reminder, please contact the Sub-Study coordinator if you have any questions or wish to exercise your rights.

Please be candid in your responses and feel free to voice any of your opinions. You may decline to answer any question. If you aren't comfortable answering a question, that is completely fine, and we can move on to the next question. You can also stop the interview at any point; and you can ask for your personal information to be deleted at any time by notifying the Sub-Study coordinator.

In this interview I will be asking you to describe any differences between your experience with facial vs. total body vitiligo. To clarify, "facial vitiligo" refers to vitiligo on your face excluding lips, scalp, ears and neck. "Total body vitiligo" refers to vitiligo on your face and from your neck and down.

This interview is made up of three different sections:

- First, we will talk about your experience with vitiligo before participation in the main study
- Next, we will talk about how your participation in the main study has impacted your life
- Finally, we would like to get your feedback on one of the questionnaires that you completed multiple times at your doctor visits during the main study

I will be sharing my computer screen for a few sections of the interview and will be using a platform called WebEx to do so. I'd like to make sure you are connected to WebEx before we begin. If you are not familiar with it, WebEx is a screen sharing program that allows me to show you what is on my computer screen. While I have control of the application, I can move the mouse, open and close programs, type on screen, etc. – and you can see everything that I am doing on my computer. Do you have access to a computer or tablet that is connected to the Internet?

[SET UP SCREEN SHARING]

The plan is to audio-record this conversation today so that I am able to focus on our conversation. The interview will be transcribed, which means we will produce a written file of our conversation word for word, and any information that will identify you personally will be removed. With that said, confidentiality is very important to us, so please try not to use the names of friends or family (or any doctors or nurses) in any of your responses during the interview.

Do you have any questions before we begin? *(Pause for questions)*

[START RECORDING]

II. Patient Background (5 minutes)

(Purpose: to initiate a comfortable dialogue with the respondent)

I would like to start by asking you a few questions about yourself.

1. How old are you now?
2. What is your current employment status?
 - a. *PROBE: full-time / part-time / not working but looking / not working and not looking, on disability, retired, in school, etc.*
3. Can you tell me what words you typically have used to describe your condition?
 - a. How have you referred to your vitiligo when you mention it to others?
 - i. *PROBE: general vitiligo (e.g., “my skin condition”, etc.)*
 - ii. *PROBE: symptoms (e.g., spots, skin blotches/patches, etc.)*

[Note to moderator: Use the patient’s own language / description when referring to vitiligo moving forward]
4. How many months/years ago were you officially diagnosed with vitiligo?
5. How many months/years ago did you first start thinking about receiving treatment for your vitiligo? Why?

- a. Did you receive any treatments for your vitiligo prior to enrolling in the trial you <recently completed/are currently participating in>? [**Note to Moderator: Patients completing the interview at Week 24 who have rolled into the extension phase may consider their study participation as ongoing**]
 - i. *PROBE: orals, topicals, procedures, etc.*
 - ii. *IF YES: Were you satisfied with the improvement of your previous treatment(s)?*
 1. *PROBE: % re-pigmentation and cosmetic improvements*
 - iii. *IF YES: Why did you stop using your previous treatment(s)?*
 - iv. *IF NO: Why not?*

III. Patient Experience pre-trial enrollment (10-15 minutes)

(Purpose: to gauge the impact of vitiligo in the patient's life leading up to trial enrollment)

[DISPLAY PATIENT'S BASELINE PHOTOS]

For the next set of questions please refer to the photos on your screen. The baseline photo is from right around the time that you enrolled in the main study, but before you started taking the study medication.

1. What was your vitiligo like at that time?
 - a. *PROBE: color, shape, location, borders of lesion, and progress of patches of light skin*
 - b. How was your facial vitiligo compared to that on the rest of your body?
 - c. Apart from lesions, did you have any other symptoms connected to your vitiligo?
2. What impact, if any, did <total body vitiligo (including face)> have on your life?
 - a. *PROBE: importance of color, shape, location, borders of lesion, and progress of patches of light skin*
 - b. How, if at all, did it impact your emotional health? **PROBE (only if not spontaneously mentioned):** *anxiety, depression, insecurity, low self-esteem, anger, shame, isolation, stress etc.*
 - i. If impact present and time permits – When did you first experience that it impacted your emotional health (age, kindergarten, high school, college etc.)?
 - c. How, if at all, did it impact your physical functioning? **PROBE (only if not spontaneously mentioned):** *inhibition of activities, sleep disturbance, itching, pain, tolerance of sun exposure, etc.*

- i. If impact present and time permits – When did you first experience that it impacted your physical functioning (age, kindergarten, high school, college etc.)?
- d. How, if at all, did it impact your social functioning? PROBE (**only in not spontaneously mentioned**): *social, romantic relationships etc.*
 - i. If impact present and time permits – When did you first experience that it impacted your social functioning (age, kindergarten, high school, college etc.)?

[Repeat question 2 for facial vitiligo asking the patient to focus on burdens unique to their facial vitiligo.]

- 3. When you first enrolled in the trial, how did you define meaningful improvement of your vitiligo?
 - a. PROBE (**only if not spontaneously mentioned**): *% improvement overall, particular body part, overall impression etc.*
- 4. When you first enrolled in the trial, which part of your body, if any, was more important for you to improve? Why?
 - a. On a scale of 0 to 10, where 1 is “not at all important” and 10 is “extremely important”, how important was it for you to improve the vitiligo on your face?
 - b. On a scale of 0 to 10, where 1 is “not at all important” and 10 is “extremely important”, how important was it for you to improve the vitiligo on other parts of your body?
- 5. Have you sought or been offered psychological counseling due to your vitiligo?
 - a. Would psychological counseling be beneficial to you?

IV. Impact of Treatment (15-25 minutes)

(Purpose: To get an unaided picture of the impact of the trial on the patient’s life)

[Note to moderator: In the section below, remind the patient of the dates associated with when they began study medication and when they completed their week 24 or week 52 visit (depending on interview time point).]

[DISPLAY PATIENT’S WK 24 OR WK 52 PHOTOS]

For the next set of questions, I would like to ask you about changes in your vitiligo that may have occurred in the time between starting the study medication and completing the <6 month/1 year> visit>.

1. What changes in your vitiligo, if any, did you notice at the time of your <6month/1 year> visit?

[Note to Moderator: In addition to the picture(s) of the patient's vitiligo at week 24 or week 52 (depending on interview timepoint, now display the VNS scale and response provided by the patient at the relevant timepoint)]

2. Please review the displayed question and your response to this question at your <6 month/1 year> visit. Was this change meaningful to you? Why or why not?
 - a. **[Note to Moderator: Systematically review all other response options and for each response, ask:]**
 - i. Does the response represent a meaningful change?
 - ii. Is the change a positive or negative outcome?
 - b. What would no change mean to you?
 - i. Would no change be a positive or negative outcome?
3. Overall, were you satisfied with the effect of the treatment on your vitiligo? Why or why not?
 - a. *PROBE: importance of color, shape, location, borders of lesion, and progress of patches of light skin*
 - b. *PROBE: If not mentioned spontaneously, ask patient to consider impact of change on emotional health, physical functioning, and social functioning*

Now I would like to focus on changes in your total body vitiligo (including face).

4. What changes, if any, did you notice in your <total body vitiligo (including face)> at the end of the <24/52> weeks of treatment?
 - a. Were these changes meaningful to you? Why or why not?
 - i. If not, what could have made them more meaningful?
 - b. *PROBE: color, shape, location, borders of lesion, and progress of patches of light skin*
5. Compared with before treatment, how noticeable was your <total body vitiligo (including face)> at the end of the <24/52> weeks of treatment?

- a. *PROBE: More noticeable, as noticeable, slightly less noticeable, a lot less noticeable, or no longer noticeable?*
- 6. How satisfied were you with these changes to your <total body vitiligo (including face)>?
 - a. On a scale of 0 to 10, where 0 is “not at all satisfied” and 10 is “extremely satisfied”, how satisfied are you with changes to your <total body vitiligo (including face)>?

- 7. What impact, if any, did changes on your <total body vitiligo (including face) > have on your daily life?

[Note to moderator: Allow patient to spontaneously mention any impacts before probing below. Note any changes from previous answers in Section III, question 3.]

- a. How, if at all, did these changes affect your emotional health?
 - i. *PROBE (only if not spontaneously mentioned): anxiety, depression, insecurity, low self-esteem, anger, shame, isolation, stress etc.*
- b. How, if at all, did these changes your physical functioning?
 - ii. *PROBE (only if not spontaneously mentioned): inhibition of activities, sleep disturbance, itching, pain, tolerance of sun exposure, etc.*
- c. How, if at all, did these changes impact social functioning?
 - iii. *PROBE (only if not spontaneously mentioned): interference with sexual relationships, social inhibition / isolation, stigmatization, discrimination, rejection, etc.*

[Repeat questions 4-7 for facial vitiligo asking the patient to focus on changes and impacts unique to their facial vitiligo.]

[Note to Moderator: The following question should be asked if time permits. However, the VNS Debriefing should take priority]

- 8. What do you think about long term or possibly life-long use of medication to treat your vitiligo?
 - a. Would you want to use a drug that might cause serious side effects, such as serious infection, if the drug reduced, but did not cure your vitiligo?
 - b. What if the drug might cause serious side effects, but could cure your vitiligo? Would you want to use it?
 - i. *PROBE (Does level of side effect risk you are willing to accept depend on the degree of improvement you would expect?)*

V. VNS Debriefing (5 mins)

I would now like to have you review the question (VNS) we reviewed earlier. Please take a minute to read through the question on your screen either silently or out loud.

1. Is it difficult to understand any part of the question? If yes, what is difficult to understand?
2. What is the question asking you to do?
3. Which response would you choose? What made you choose <response>?
4. Do you have any difficulties understanding the response options?

VI. Conclusion / Wrap-up (2-5 mins)

We have reached the end of my questions regarding your experience with vitiligo. Before we wrap-up, I want to give you the opportunity to comment on anything else that we may have not discussed today. Is there anything else you would like to share to help me better understand your experience with vitiligo? (*Pause for patient's response*)

I want to thank you for your time today; this discussion has been extremely helpful for understanding what people go through with this disease. If you have no further questions at this time, we can go ahead and end the discussion. Thanks again.

VNS Visual Stimulus

VNS: Compared with before treatment, how noticeable is the vitiligo now?

- (1) More noticeable
- (2) As noticeable
- (3) Slightly less noticeable
- (4) A lot less noticeable
- (5) No longer noticeable

Appendix S2. Study 2: Patient Interview Concept Overview

1. Time of vitiligo diagnosis

- a) Duration between noticing symptoms and receiving vitiligo diagnosis
- b) Body location of vitiligo
- c) Duration of facial vitiligo

2. Experiences with facial vitiligo

- a) Severity of facial vitiligo
- b) Changes in severity of facial vitiligo over time

3. Location of facial vitiligo lesions

- a) Changes in the location of vitiligo over time
- b) Variability (if any) in facial vitiligo across different areas of the face

4. Extent/coverage of facial vitiligo lesions

- a) Changes in extent/coverage of facial vitiligo

5. Noticeability of facial vitiligo lesions

- a) Factors contributing to noticeability of facial vitiligo (eg, color, pattern)
- b) Changes in noticeability of facial vitiligo

6. Appearance and shape of facial vitiligo lesions

- a) Changes in the appearance (eg, color) and shape of facial vitiligo
- b) Variability in color and shape of any facial lesions

7. Ease/difficulty of covering facial vitiligo lesions

8. Factors contributing to how bothersome facial vitiligo is

9. Methods for treating and covering facial vitiligo lesions (eg, medication, cosmetics)

10. Previous prescription medications or medical procedures for managing facial vitiligo lesions

11. Efficacy of previous medications/procedures for facial vitiligo

- a) Positive/negative features of previous medications/procedures for facial vitiligo

12. Outcomes of ideal treatment for facial vitiligo

- a) Meaning of improvement and what is most important for treatment to improve

13. Ranking potential outcomes of successful treatment (ie, 1–5 scale of not at all to extremely important)

- a) Reduce/eliminate facial vitiligo lesions
- b) Reduce noticeability of facial vitiligo lesions
- c) Change location/appearance/shape of facial vitiligo lesions
- d) Ease of covering facial vitiligo lesions

14. Meaningful repigmentation of facial vitiligo (ie, smallest improvement considered meaningful)