

Exploring Factors That Influence the Measurement of Patient-Reported Impacts of Alopecia Areata

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Appendix

Interview discussion guide

Section One: The impact of AA on daily life

1. To help understand your experience of living with Alopecia Areata (AA), I would like to know more about how your condition has progressed over time and what that experience was like for you. Please can you give me a timeline of your experiences from when you first went to see a doctor about hair loss up to the present day?
 - a. What were your views or attitudes toward your hair in the times before receiving your diagnosis?
 - b. What were your views about your hair following your diagnosis?
2. How does how you have viewed your hair in the past compare to how you view it now?
 - a. Why do you think you might have different views now than in the past?
 - b. When do you think these views might have changed?
3. What is your experience of a typical day living with AA currently?
 - a. What does a typical good day look like currently?
 - b. What does a typical bad day look like currently?
 - c. How, if at all, does living with AA affect any hope or optimism you experience?

- d. How, if at all, does living with AA affect your ability to bounce-back after challenges in life?
4. How, if at all, has the way that AA affects your daily life changed over time?
- a. Do you feel differently about your diagnosis now compared to when you were first diagnosed? If so, how?
 - b. How, if at all, have your priorities or perspectives in life changed since you were first diagnosed?
 - c. Are there any differences in how you see your own health now compared to when you were first diagnosed?
 - i. Have there been any other periods during your journey with AA where you would have seen your health differently than you do today?
 - ii. Are there any differences between now and other times in your journey in what a typical 'good day' would look like?
 - Would there be any differences for a typical 'bad day'?
5. From the ways we have discussed that AA can impact your daily life, what aspect of living with the condition do you feel currently has the greatest impact? Why?
- a. Has this always been the biggest impact, or has it changed over time?
How has it changed?
 - b. **If no current impact:** What aspect of living with the condition do you feel previously had the greatest impact? Why

6. Do you feel you have received any support from your social network (***e.g., family or friends***) since being diagnosed?

a. Are there support services you have accessed that have helped you manage your diagnosis or condition (e.g., patient or peer groups, information, or charity groups)?

i. What did you use these support services for?

ii. Have these made any changes in how you think about AA or how it affects your life? How so?

7. What are your hopes or expectations for any current or future treatment of Alopecia Areata?

Ask prompts a, a(i), b, and b(i) only for patients that are currently receiving specific AA treatment (as featured in the screening question: Have you received a pharmacological treatment for alopecia areata?)

a. What type of treatment have you received for AA?

i. How long have you been receiving your current treatment?

b. Have you noticed any changes to your daily life and activities after starting your most recent treatment? Please explain.

i. Are these changes meaningful to you?

- Why or why not?

Section Two: PGI

For this section you will need to screen share the below table with participants and enter their reported part 1 areas of life, part 2 scores, and part 3 point spending as they complete the PGI task.

1. We are now going to complete a three-part exercise. First, I would like you to tell me up to five of the most important areas of your life currently affected by AA. If you cannot think of five, tell me as many as you can. ***(Interview to note areas listed for reference)***
2. For each of these areas, rate the extent to which you think they are affected by AA on scale of 0 (the worst you could imagine) to 100 (exactly as you would like it to be).
3. Last, imagine that any or all of the areas mentioned could be improved. You have 60 hypothetical points to spend to improve any or all of these areas. Give more points to areas you consider more important and less to areas that are not so important. You do not have to spend points in all areas. You must spend all points and cannot spend more than 60 points in total.
 - a. How would you spend these across the areas you identified?

Part 1. List the areas	Part 2. Score the areas	Part 3. Spend 60 points

What are up to five most important areas of your life that are affected by AA?	How much is each area listed in part 1 affected by AA (0-100)?											Spend up to 60 points to show what areas you consider more or less important to improve.
1.												
2.												
3.												
4.												
5.												
The worst you could imagine	0	10	20	30	40	50	60	70	80	90	100	Exactly as would like to be

Section Three: Measuring the impact of AA

I would now like to ask you some questions to gain your view on how the impact of living with AA should be measured.

8. Over the past week have you felt self-conscious about hair loss? Please answer on a scale from:

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

b. Why did you select this response option?

- i. Please talk me through an example from your experiences to help us understand your answer.
- ii. Is there any time you would have responded differently (e.g., before diagnosis, after diagnosis)? Why or why not?
 - To what extent, if at all, do you think your response might be affected by any hair regrowth that might be seen following a successful treatment?

9. Over the past week have you felt embarrassed about hair loss? Please answer on a scale of:

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

b. Why did you select this response option?

- i. Please talk me through an example from your experiences to help us understand your answer.
- ii. Is there any time you think you would have responded differently (e.g., before diagnosis, after diagnosis)
- iii. If you received treatment that worked to regrow your hair, do you think you would pick the same or a different response? Why?
 - How much regrowth would it take for you to answer this question differently?
 - How long would the regrowth need to last for you to answer question differently?

10. Over the past week have you felt sad about hair loss? Please answer on a scale of:

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

a. Why did you select this response option?

- iv. Please talk me through an example from your experiences to help us understand your answer.
- v. Is there any time you think you would have responded differently (e.g., before diagnosis, after diagnosis)
- vi. If you received treatment that worked to regrow your hair, do you think you would pick the same or a different response? Why?

- How much regrowth would it take for you to answer this question differently?
- How long would the regrowth need to last for you to answer question differently?

11. Over the past week have you felt frustrated about hair loss? Please answer on a scale of:

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

a. Why did you select this response option?

- Please talk me through an example from your experiences to help us understand your answer.
- Is there any time you think you would have responded differently (e.g., before diagnosis, after diagnosis)
 - If you received treatment that worked to regrow your hair, do you think you would pick the same or a different response? Why?
 - How much regrowth would it take for you to answer this question differently?
 - How long would the regrowth need to last for you to answer question differently?

12. Over the past week have you limit participation in outdoor activities because of hair loss? Please answer on a scale of:

Not at all	Very little	Somewhat	Quite a bit	Completely (did not do any outdoor activities <u>because of hair</u> <u>loss</u>)
1	2	3	4	5

a. Why did you select this response option?

- i. Please talk me through an example from your experiences to help us understand your answer.
- ii. Is there any time you think you would have responded differently (e.g., before diagnosis, after diagnosis)
- i. If you received treatment that worked to regrow your hair, do you think you would pick the same or a different response? Why?
 - How much regrowth would it take for you to answer this question differently?
 - How long would the regrowth need to last for you to answer question differently?

13. Over the past week have you limited exercise because of hair loss? Please answer on a scale of:

Not at all	Very little	Somewhat	Quite a bit	Completely (did not do any physical activities <u>because of hair</u> <u>loss</u>)
1	2	3	4	5

a. Why did you select this response option?

- i. Please talk me through an example from your experiences to help us understand your answer.
- ii. Is there any time you think you would have responded differently (e.g., before diagnosis, after diagnosis)
- i. If you received treatment that worked to regrow your hair, do you think you would pick the same or a different response? Why?
 - How much regrowth would it take for you to answer this question differently?
 - How long would the regrowth need to last for you to answer question differently?

14. Over the past week have you limited interaction with others because of hair loss?

Please answer on a scale of:

Not at all	Very little	Somewhat	Quite a bit	Completely (did not interact with others at all <u>because of hair</u> <u>loss</u>)
1	2	3	4	5

a. Why did you select this response option?

- i. Please talk me through an example from your experiences to help us understand your answer.
- ii. Is there any time you think you would have responded differently (e.g., before diagnosis, after diagnosis)
- iii. If you received treatment that worked to regrow your hair, do you think you would pick the same or a different response? Why?
 - How much regrowth would it take for you to answer this question differently?
 - How long would the regrowth need to last for you to answer question differently?

15. Would you change or add anything to these questions to make it more relevant to your experience?

16. Would you make any changes to the timeframe of one week? If so, why?

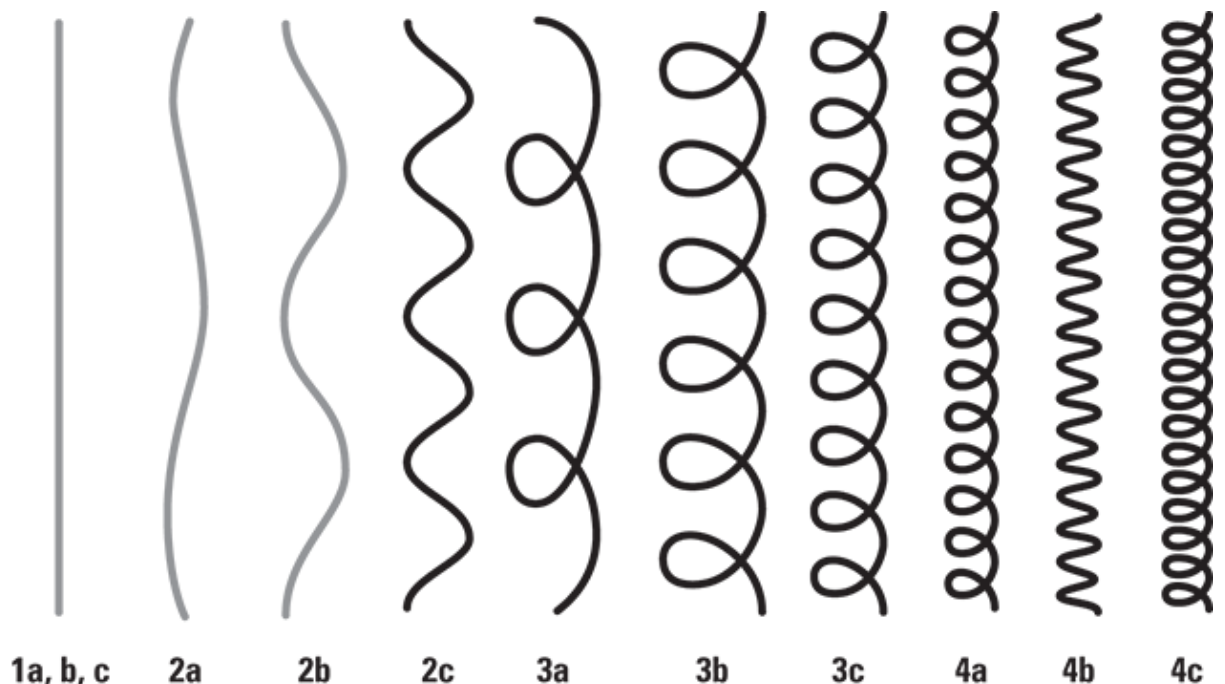
17. Would you change or add anything to the responses available for this question?

18. Would it be more appropriate for you and your experiences to answer some or all of questions in terms of intensity (e.g., none, a little bit, somewhat, very much) instead of frequency?

Section Four: Background questions and close out

In this last section, I would like to go through some background questions with you.

4. At what age were you first diagnosed with Alopecia Areata?
5. How old are you now?
6. What is your main current occupation or productive activity (e.g., studying, paid work, caring for a family member, or volunteering)?
7. Which of the follow images do you think best represents your hair type?



Is there anything else you would like to mention that could help us to understand your experiences of living with AA that we have not covered, or that you feel you have not had the opportunity to say?

A global pharmaceutical company called Pfizer funded this study. We did not tell you the name of the funding company before your interview in case knowing this information

influenced any responses. The funder will not be made aware of your identity or have access to any of your personal information.

Thank you for time today, your contribution is greatly appreciated. Your participation in this study has been entirely voluntary. If you decide later to leave this study, please contact me or the recruitment contact that invited you to participate so that the researchers can delete any information that you have provided. If you chose to do so, you will not be penalised or lose any benefits that you are otherwise entitled to.