AMEDA Interview Guide

Patients with alopecia areata

Thank you for agreeing to take part in the study.

The aim of this study is to investigate the treatment pathways of adult patients with alopecia areata. In doing so, we would like to learn about different stages in the treatment pathway and, in particular, find out more about access to medication for these conditions. We also want to uncover inequalities so that we can address and minimize them later.

In order to gain a comprehensive insight, today we would like to look at your entire history with alopecia areata - what you have experienced (and also taken) so far. We don't just want to look at certain stages, but focus in particular on how decisions and paths were taken.

While you are telling me your story, I will take a few notes on a PowerPoint slide to make it easier to follow the process and illustrate your journey. So please don't be surprised if I don't look at the camera in the meantime - I'll continue to listen to you but will make notes on the second screen. During the conversation, I will share my screen from time to time so that we can take a look together. This illustration does not have to be worked out down to the last detail, but should rather serve as an aid and orientation.

We look forward to learning more about your personal treatment path and getting to know your views. There is no right or wrong. Tell us openly what you would like to tell us about the topic.

I will keep asking questions and drawing our attention to certain aspects - although I will try to keep my own speaking time to a minimum so that we can learn more about you and from you.

We will record our conversation and then write it down verbatim. However, this will be pseudonymized, i.e. all names, places and the like will be omitted so that no conclusions can be drawn to your person. Everything you say remains confidential. Apart from the pseudonymized data (e.g. verbatim quotes to substantiate a statement), none of the information provided here will be shared with anyone outside the study team.

If we bring up anything you don't want to talk about, please let us know.

The interview will last a maximum of 90 minutes - if we are finished earlier, this is not a problem and is at least as informative for us as a longer appointment. The duration always depends very much on the individual treatment history. In any case, the interview will not take longer than 90 minutes. However, you can stop at any time or take a break.

Do you have any questions? Then I would start the recording now.

Introductory questions

To start with, I would like you to **tell** me **briefly** how you are currently feeling with your alopecia areata.

I would like to learn more about your personal **patient history** - from the first symptoms to the present day.
If you were to divide this time into stages or phases, what would they be? Please tell me about the **phases you** have gone through **since the beginning of your illness**.

Details of patient history

Explore individual phases further

- What did you **experience** during this time with regard to the treatment of AA?
- What **steps** have you taken? / What **stages** were there within this phase?

Focus on: subjective feelings, personal experiences, reasons:

- What **prompted** you to ...?
- How did it come about that you ... visited / ... took / ...?
- Please tell me how you to this **decision**.
- How did it come about that you decided **for/against** the [doctor's visit/medication/other help/...]? have decided?
- What was **important** to you when you made your decision?
- *Downstream: How did you feel about [symptoms/stress/visits to the doctor/medications/side effects/...]?*

Request specific area/settings

Further inquiries about specific areas/settings, whether they played a role/what role they played:

- To what extent did XX play a **role** in your patient history?
- What **experiences** have you had at/with XX?
- Feel free to tell me more about your **journey** to XX.
- Please tell me more about your **experience** at XX.
- Why have you **no experience** with XX?

Areas/Settings:

- *General practitioners*
- *Dermatologists*
- *Medication*
- *Other products (including basic care)*
- *Pharmacy*
- *Self-help groups*
- *Internet*
- *Alternative practitioner:in and other alternative medicine*
- *Other*

Overall view

When you look back on your previous patient history, would you have liked **something** to have **gone differently**?
(happened earlier / happened later / left something out / missed something / ...)

Differences in care

Towards the end, I would like to take a broader view. As I mentioned earlier, we would like to find out what differences there might be in care. I would therefore now like to look at specific aspects that may have affected your situation with alopecia areata.

In the following, I will mention some personal or disease-related characteristics and would like to know from you how these affect how you feel about your alopecia areata, whether you go to the doctor and how you are treated.
Of course, you can talk about your own experience and history, but perhaps you have already noticed some of these aspects or you can imagine situations in which they might come into play.
Follow-up: To what extent could you imagine that these characteristics could have an impact on the care situation of patients

- Severity of alopecia areata
- Comorbidities
- Health insurance
- Place of residence / region
- Age
- Family situation (partnership, children) and living situation (with family, living alone)
- Professional background and educational qualifications
- Gender

Are there any other personal or disease-related characteristics that you feel have an impact on the care of your alopecia areata?
Or are there other characteristics that you can imagine having an impact on the patient's care situation?

Conclusion

Is there anything else that you consider important that has not yet been discussed?
(with regard to your own patient history *or the care of patients with alopecia areata as a whole*),

Query of socio-demographic data for our sample description:

- Estimation of the participant's hair loss (in %)
- Estimation of the participant's:in by proportion of total hair missing (in %)
- Age
- Gender
- Highest school-leaving qualification
- Place of residence
- Duration of the disease
- Type of insurance (private/statutory)

Clarify at the end:

- Account details for expense allowance
- Note that payment of the expense allowance can take up to 8 weeks
- Open questions
- Information that participants will receive a brief summary of the study results at the end of the study

I would like to thank you very much for taking the time to conduct this interview with me and for your openness during our conversation. These are very important insights for us.