

Qualitative Patient Interview Topic Guide

Part 1 – Treatment of HS (previous experiences)

When were you diagnosed with HS?

Since then, what have you used to help manage your HS?

Have you done/changed anything else to manage your HS?

We would like to know about the treatments and any surgery for HS that you have previously received before taking part in the THESEUS study.

Have you found any treatments/changes to be beneficial?

Is there any that you have not found very helpful?

Have you had trouble with any treatment? [such as... any side effects; difficulties using a treatment; problems with wound healing; any that you have given up on?]

Are there any treatments that you have wanted to try? But haven't? Why?

Do you have a favoured treatment? Why is this?

How well do you think that your HS is managed?

How do you feel about trying different things in managing your HS?

How confident are you in talking to your GP (or other healthcare providers) about HS?

How well do you think that HS is understood?

Part 2 – Treatment in the study

Now can we talk specifically about the treatments that you have experienced in the THESEUS study, which of the treatments have you received?

How did you come to have this treatment? Did you choose this (know about it previously)? Have you had it before? Did the doctor recommend it?

What did you know about it?

Would you have liked to have tried another treatment? Why didn't you?

How has the treatment gone?

Has it been beneficial? Better than other treatments?

Has it been acceptable? Was it how you expected it to be – better / worse; more / less pleasant? Could you cope / was it manageable?

Have you experienced any difficulties? Any side-effects? Any issues with taking medication, etc.? any pain due to the treatment?

Do you think this treatment will make a difference to you in the long-term?

For medication (ongoing use): Do you want to continue this treatment after the study? How would you build this treatment into your normal care?

For surgery (one off treatment): Would you use this treatment again? When might you want it / what might prompt its use?

Would you choose this treatment if you could choose again?

Would you recommend it to another person with HS?

Part 3 – Taking part in our research

Why did you agree to take part in our research study?

Because of your HS? To get new/different treatment? Wanting to know more about HS? Frustrated with current care?

Because you want to 'give something back' to the NHS?

To help other people with HS?

When deciding whether to take part in the study, did you have any thoughts or concerns that taking part in the research might affect your clinical care – better? worse?

How have you found taking part in the research?

Has it been a positive experience? has there been any difficulties or frustrations?

Have you found anything off-putting or difficult to manage?

Was there anything that we asked that felt unreasonable (clinic visits, form filling, etc.)

Is there anything that we might change to make a similar study better for those that take part?

How well do you feel that you understand what we did in the research?

Was the information that we gave you helpful? Was there anything that was not clear?

Our plan is to run a larger study in the future, do you think we should include the treatment that you had in this study?

Our larger study may involve randomising patients to different treatments – what do you understand about randomisation? (explain if do not understand) How would you feel about being randomly assigned a treatment in a HS study?

{hypothetically} would you take part in another HS study? Why? Why not?

Healthcare staff interview topic guide

Part 1 – Treating HS (Prior to THESEUS)

1. What are the key challenges of managing patients with HS?

Prompts: Which of these relate to the:

- i) diagnosis
- ii) treatment options
- iii) HS symptoms for the patient
- iv) HS emotional impact
- v) Challenging consultations/discussions with patients (e.g., smoking, weight)

2. How might HS management be improved for patients?

3. Do you have a preferred management approach for HS?

Prompts: Why is this your preferred option?

Is this more effective/better received/easier to deliver?

Have you had trouble with any treatments?

Difficulties with commissioning/delivery?

Difficulties with poor clinical outcomes?

Part 2 – Treatment during THESEUS

4. Which of the five treatments in the study were offered by your site?

Prompts: What is your assessment of the treatment options available in THESEUS?

PROS and CONS of each?

Your assessment of treatments new to you or your site? Do you want to keep these?

Any difficulties with new treatments introduced to your site?

Any that you were unable to deliver, why?

5. How were the options received by your patients?

Prompts: What sort of discussions did you have with them? What factors were important to patients?

Do you agree with these?

6. Has involvement in THESEUS changed your practice in any way?

Prompts: Is this to do with new treatment options? More knowledge/awareness?

Part 3 – Taking part in our research

7. How did you find delivering the THESEUS study?

Prompts: Generally have you found participation in the THESEUS study to be a positive experience?

Have there been any difficulties or frustrations?

Were there any lessons learnt?

- i. Identifying/recruiting patients
- ii. Discussing the treatment options with the patients
- iii. Discussing the aspects of the trial with the patients
- iv. Maintaining their involvement
- v. Troubleshooting their problems or addressing their queries/concerns (did participants experience any difficulties?)

8. What impact did the covid-19 pandemic have on delivering the study?

Prompts: Delays to surgery, remote appointments, experience of getting patients to take photos of their HS, patient concerns about coming to the site...

9. How did you find the outcome measures used in the study?

Prompts: Do you think that we collected the right outcome data? If not, what do you think we should have collected?

Any comments on the timeframe of the delivery and follow up of the outcome measurements

Did you have any practical difficulties with the measures that we used?

Do you think that the participants have had any difficulties with our research processes? Do you think that the study burden associated with the measures that we collected was appropriate? Was it acceptable to participants?

10. Do you feel you and your site were supported by the core THESEUS team? Why is this?

Prompts: What did work well? Was there anything that didn't work so well? If you had difficulties during the trial, did you contact the study team?

Were your problems dealt effectively by the study team?

How could we improve the support we provide to participating sites?

11. Do you think we need future trials in HS? Why is this?

Prompts: Which of the treatments offered in THESEUS do you feel should be included in a future clinical trial?

Why?

Should these be available to all patients or specific patient groups?

What other treatments, that have not been included in THESEUS, should we include in future trials?

Would you be willing to take part in a future HS trial?

Do you have any criteria for future involvement (ie - only if certain options were included)?

Would you have any difficulty randomising your patients to a trial?

- Anything else you want to add