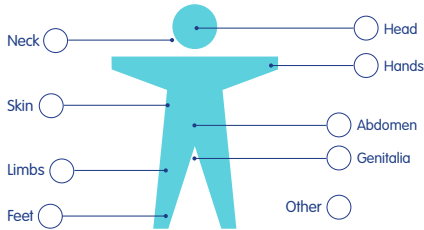


This questionnaire is to help you and your clinical team understand your HAE better and make informed decisions together about treatment and management. Please fill in the questionnaire ahead of your HAE appointment.

1 How many episodes have you had on each site in the past three months?
(Please mark on the body)



2 How many times did you use rescue medications during the last 3 months?

Icatibant -----

C1-esterase inhibitor -----

3 What medication were you taking in the LAST THREE MONTHS as **prophylaxis**, indicate start date: None

| Medication | Start date | Frequency of administration |
|---|------------|-----------------------------|
| Tranexamic acid | | |
| Danazol | | |
| Oxandrolone | | |
| Berotrastat | ▼ | |
| Lanadelumab | | |
| Regular C1-Inhibitor (for prophylaxis only) | | |

Reporting of side effects

If you get any side effects from these medicines, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at <https://yellowcard.mhra.gov.uk/> By reporting side effects, you can help provide more information on the safety of these medicine. Berotrastat is subject to additional monitoring. This will allow quick identification of new safety information. You can help by reporting any side effects you may get. See <https://yellowcard.mhra.gov.uk/> for how to report side effects.

4 ANGIOEDEMA CONTROL TEST

a In the last three months: (please tick)
How often have you had an HAE attack?



b How much has your quality of life been affected by your HAE? (please tick)



c How much has the unpredictability of your HAE bothered you? (please tick)



d How well is your HAE controlled by your current treatment? (please tick)



5 How would you describe the overall severity of HAE attacks/symptoms in the past 3 months? (please tick)

- No attacks
- Very mild
- Mild
- Moderate
- Severe
- Very severe

Thank you to the Immunology department at Barts Health NHS Trust and HAEUK for their collaboration in the development of this resource.

6 Have you had any new symptoms that you think may be due to current/new treatment?

(please tick) No Yes

How long after starting new treatment did you experience this?

How long did it last?

If it is recurring, how often do you have this/these new symptom(s)?

Have there been any occasions when you stopped taking your medication or reduced your dosage due to new symptoms? If so, please provide details on when this happened and what changes you made to your dosing.

Have there been any days where you have forgotten to take your treatment?

Please provide details on when this occurred and for how long you went without taking treatment?