

HEREDITARY ANGIOEDEMA (HAE)

PATIENT IMPACT SURVEY SUMMARY

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BE **HA**ERD.

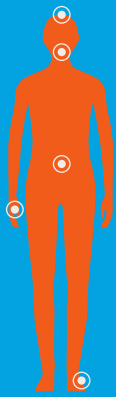


This document was developed and funded by Takeda in collaboration with HAE UK

ABOUT **HAE**

HAE is a **rare genetic condition** which affects an estimated **1,300** people in the UK.¹

It is **lifelong**, multifaceted, and potentially **life-threatening**.²



HAE symptoms include episodes of **swelling** in any part of the **body** including the hands, feet, face, abdomen, and airway.²

ABOUT THE PATIENT IMPACT SURVEY

To understand more around the **psychological, physical, and social** impact on people affected by HAE, Takeda UK, in partnership with HAE UK, gathered **insights** from **109** people, including people **living with HAE**, and their **carers**.



The survey data provides a better **understanding** of the **burden** of HAE for people **affected**, and highlights **gaps in the care** they receive, that should be addressed.³

WE BELIEVE THAT EVERY PERSON LIVING WITH HAE IN THE UK MUST HAVE **EQUITABLE ACCESS** TO **HIGH-QUALITY TREATMENT** AND CARE, NO MATTER WHERE THEY LIVE, SO THAT **EVERY PATIENT** IS ABLE TO LIVE, AND NOT JUST EXIST, WITH THEIR CONDITION.



OUR AMBITION FOR CARE FOR PEOPLE LIVING WITH

1. All patients must be offered the full range of clinically effective treatments, alongside regular treatment reviews over their lifetime, so they can strive to achieve total control of the disease and the best possible quality of life.

Supporting survey data:



of participants feel **easier access** to a **range of treatments** would help better manage their HAE.

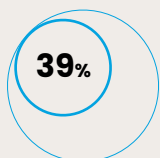
n=109

Our policy ask(s):

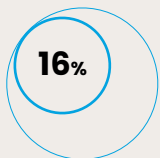
- 1 The NHS should align its Clinical Commissioning **Policies** for HAE with the **Government's national rare disease aspiration** for every patient to get the treatment they need.
- 2 **Specialist services** should provide access to **regular treatment reviews** so that ongoing management reflects the **changing needs of HAE** patients over their life course.
- 3 NHS services should collect **patient-reported outcome** and **quality-of-life data** in order for the impact of HAE treatment to be more **holistically considered** in the management of individual patients.

2. Shared decision-making between clinical teams and patients at every stage of the care pathway should be prioritised to enable patients to best manage their own condition.

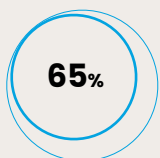
Supporting survey data:



of participants feel **more interactions** with their **HAE clinical team** would help better manage their HAE.



have **never heard about any of the support** available to them.



agree to some extent that **people in their social circle do not understand** how HAE affects them.

n=109 (all)

Our policy ask(s):

- 1 Best practice should follow NHS England's **shared decision-making guidance** to better **standards of care** in all healthcare settings throughout the patient journey.
- 2 Co-created **patient education materials** should be **developed** and **rolled out** to support patients to confidently **engage** with specialist care **services**.
- 3 Patients should be directed to the HAE UK **website as an education resource** to ensure they are equipped with **self-management tools** to support shared decision-making.

3. Clinical professional awareness of HAE in all healthcare settings must improve, particularly in A&E, so that patients presenting with acute and potentially life-threatening attacks receive the most appropriate care.

Supporting survey data:



81% of surveyed people have experienced at least **one HAE attack** in the last **3 months**. Of those having attacks, the majority (82%) self-reported that their **symptoms are at least fairly severe**.

Surveyed people living with HAE have **6 attacks** on average in past **3 months**.

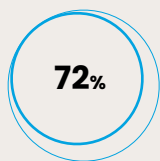
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Our policy ask(s):

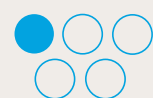
- 1 A **universally recognised HAE ID** should be introduced for patients to present in an **A&E setting** post-diagnosis to help ensure patients receive the **care they need** in an **emergency** presentation.
- 2 **Educational intervention** should be introduced during **medical training** to increase **awareness** of the signs of HAE in all **healthcare settings** but especially in **A&E**.
- 3 Online and easily accessible **education materials** on the **signs and symptoms** of HAE should be more widely **publicised** to healthcare professionals.

4. Improved access to psychological support when a patient needs it would help those with HAE to better manage the mental and physical health impact of living with their condition.

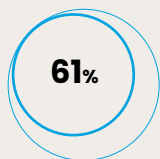
Supporting survey data:



72% of surveyed people living with the effects of HAE and their carers feel their HAE **impacts their mental health** at least to some extent.



1 in 5 (21%) of surveyed people living with the effects of HAE and their carers would find **one-to-one therapy** useful to help better manage their HAE.



61% of surveyed people living with the effects of HAE and their carers **feel worried** about having an **HAE attack** in next 12 months.

n=109 (all)

Our policy ask(s):

- 1 The NHS should provide greater **access to psychologists** for all HAE patients. This would especially help patients who may not **regularly** engage with the **health system**, other than in crisis.
- 2 Access to **psychological support services** should be embedded in patients' **management plans**, particularly to help address **anxiety** amongst patients about changing their treatment.
- 3 **Specialist psychological intervention** should be targeted to those most in need, where the condition may have a significant impact on their mental and physical health.