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aHUS Awareness Day 2026: aHUS Community Consultation on Proposed Nomenclature Change

Abstract

Introduction

International aHUS Awareness Day 2026 focused on proposed nomenclature change from atypical hemolytic uremic syndrome (aHUS) to complement-mediated thrombotic microangiopathy (CM-TMA or cTMA and other variants). This report presents the first structured patient and carer consultation on the issue, including their voting results and reasons and key threats and opportunities.

Method

aHUS community members were offered four voting options (for, against, conditional on retaining "aHUS" as part, or undecided) via public video contribution, private email or Facebook direct messaging and commenting. The invitation, shared on social media, reached several thousand people; responses closed on 23 September 2026.

Results

Of 63 respondents to this aHUS Awareness Day survey project, conditional support (retaining aHUS as part) was highest (51%), followed by against (32%), undecided (15%) and for (2%). Video yielded more conditional votes than Email. Loss of the current and familiar name given as the reason along with name continuity needed for awareness, care access and connection to the community dominated the threats from change.

Discussion

Findings indicate predominantly acceptance of a change happening but with salient concerns rather than polarised rejection. Addressing dominant reasons and threats could shift conditional respondents toward support. Patient engagement, dual-naming transitions and clear safeguards/contingencies for perceived risks are particularly important considerations. Furthermore, a name change for a disease which is life threatening and demanding urgent care has additional practical risks than for a non-acute but slowly progressing disease. Historical precedents confirm that renaming succeeds only with structured consultation and continuity measures,

Conclusion

Results from 63 aHUS patients and carers showed predominantly conditional support (51%) or opposition (32%) to renaming aHUS as cTMA. Key concerns centred on loss of familiar identity, treatment access risks, and community continuity. Addressing these threats through transitional strategies may increase acceptance, although the modest sample limits generalisability.

Key Findings.

1. **There was minimal support for a complete change of name and nearly a third of participants were unequivocally against any change.**
2. **Just over half of patients accepted name change if aHUS was somehow retained in the new name.**
3. **The highest reasons given were loss of familiarity, awareness, care access. Entitlement to a complement inhibitor, and potential misdiagnoses.**
4. **Most saw a name change and the way it would be introduced as a threat to their lives, and few saw any benefits.**
5. **Most participants preferred the open and visible video pathway to give their views.**

Introduction

aHUS Awareness Day is observed annually on 24 September. Established eleven years ago by the aHUS Alliance, the day aims to increase global recognition of atypical haemolytic uraemic syndrome (aHUS).[1]

Although the formal descriptor remains " haemolytic uraemic syndrome" [2], the abbreviation aHUS has become a widely recognised disease identity since advocacy efforts began in the early 2000s.

In recent years, scientific and clinical discussions have proposed replacing aHUS with more precise, mechanism-based terms such as complement-mediated thrombotic microangiopathy (cTMA or CM-TMA). Proponents argue that "atypical" is outdated and that the current name describes effects only and does not adequately reflect underlying causal pathophysiology or the full clinical spectrum (including non-kidney presentations). [3]

The 2026 aHUS Awareness Day theme focused on these nomenclature plans. The aHUS patient and carer community was invited for the first time to express its views and to vote on the proposed potential change.[4]

Methods

The aHUS community was offered four voting options:

1. For a name change
2. Against a name change
3. Conditional support (specifically, agreement provided that "aHUS" is retained in some form within the new name)
4. Undecided

Those voting were also asked to give the reason for their choice.

Participation was possible through two channels:

- Public contribution to an Awareness Day video (name, country, photograph, short statement, and vote) ,
- Private email vote submitted to aHUS Alliance Global Action

The invitation was disseminated via aHUS social-media awareness posts and newsletters which collectively reached several thousand individuals.[5] Responses were accepted until 21st September 2026 for video and 23 September 2026 for email votes. The launch article received 400 views and yielded 63 responses (16%).

During the social media promotion, the email option was extended to include Facebook direct messages for participants' convenience. Some respondents commented directly on a promotional post and were asked for permission to include their views.

Results

A total of 63 responses were entered to an Excel spreadsheet, coded and analysed and presented in the following three figures. Votes and voting pathways were examined by communication route (video versus email) in Figure1, the associated reasons provided by respondents were categorised and quantified in Figure 2, and the resulting threats and opportunities identified by respondents were tallied in Figure 3.

Figure 1. Votes by option and pathways taken

Route	For	%	Against	%	Conditional	%	Undecided	%	Total	%
Video	1	2	11	17	22	35	5	8	39	62
Email	0	0	9	14	10	16	5	8	24	38
Total	1	2	20	32	32	51	10	16	63	100

Of the 63 respondents, 39 (62%) responded via the video route and 24 (38%) via the email route. Overall, 1 respondent (2%) voted for change, 20 (32%) voted against change , 32 (51%) voted for conditional change, and 10 (16%) remained undecided.

Within the video route (n = 39), the distribution was: for = 1 (2% of total sample), against = 11 (17%), conditional = 21 (35%), and undecided = 5 (8%). Within the email route (n = 24), the distribution was: for = 0 (0%), against = 9 (14%), conditional = 10 (16%), and undecided = 5 (8%).

Thus, conditional (retaining aHUS somehow) responses predominated overall and were particularly frequent among video respondents, while against responses were equally frequent across the two routes.

Figure 2. Votes by option and reason for choice.

	Reason	For	Against	Conditional	Undecided	Total	%
1	Could confuse doctors more than they are and misdiagnoses.		2	4	2	8	13

2	Do not know enough of what is planned.				3	3	5
3	Concern about current patient platforms becoming invisible to new patients.		2	3		5	8
4	Risk of losing entitlement to complement treatment (e.g. insurance).		2	7	1	10	16
5	Loss or no confidence in managing the major change proposed.				2	2	3
6	Worry that division will risk access to research funds.		1			1	2
7	Evolve but preserve aHUS continuity for awareness and care access.		2	9		11	17
8	Diverse names could break existing community cohesion.			1		1	2
9	Name loss will cause confusion for those with idiopathic aHUS.			1		1	2
10	Loss of current name which is familiar.		9	6		15	23
11	Is science advanced enough to make accurate categorisations (secondaries).			1		1	2
12	Wrong priority, should focus on speeding up diagnosis.		1			1	2
13	Needed for tailored care.	1				1	2
14	Can create greater clarity for patients .				1	1	2
15	No reason given.	0	1		1	2	3
	Total	1	20	32	10	63	

In Fig. 2 respondents' stated reasons were coded into fourteen discrete categories (1-14 -Appendix A) plus a residual "no reason given" category. The most frequently cited reasons were Reason 10 –" Loss of current name which is familiar" (n = 15, 23.3% of the sample; against = 9, conditional = 6). Reason 7= "Evolve but preserve aHUS continuity for awareness and care access", (n = 11, 18 %; against = 2, conditional = 9) and then Reason 4-"Risk of losing entitlement to complement treatment" (e.g. insurance)" (n = 10, 16%; against = 2, Conditional = 7, undecided = 1).

Other reasons occurred at lower frequencies: Reason 1- "Could confuse doctors more than they are and misdiagnose". (n = 8, 13.0%; against = 2, conditional "= 4, undecided= 2); Reason 3- "Concern about current patient platforms becoming invisible to new patients" (n = 5, 8%; against = 2, conditional = 3), Reason 5 "Loss or no confidence in managing the major change proposed"(n=2 (3%) all undecided) and "No reason" (n = 2, 3%; against = 1, Undecided = 1). The remaining reasons (6, 8, 9, 11, 13 and 14) accounted for a single response each (2%).

Figure 3 Threats and Opportunities and reasons relevant to each

	Threat from:	No.	%
A	Concern about the capability of front line health care professionals to fully understand the change	8	13
B	Loss of a familiar name	26	41
C	Loss or division of a visible patient community	6	10
D	Concern about ability to manage a project of this scale	5	8
E	Risks to patient management	12	19
F	Loss of research funds	1	2
G	Tackling wrong priority	1	2
	Total	59	

	Opportunity for:	No.	%
H	Tailored Care	1	2
I	Greater clarity for patients	1	2
	Total	2	4

2 No reason given

The reasons given by respondents also identified threats and opportunities, which were grouped into nine categories (A–I) plus a residual no reason given. (Appendix B) . Category B Threat- . "Loss of a familiar name" was by far the most frequently cited (n = 26, 41% of the sample). Category E Threat - "Risks to patient management followed (n = 12, 20%), with Category A Threat – "Concern about the capability of front line to fully understand the change" (n=8 (13%)); and then Category C Threat "Loss or division of a visible patient community" = 6 respondents (10%). Category D Threat- "Concern about ability to manage a project of this scale" was mentioned by 5 respondents (8%). Two respondents (3.3%) identified no threats or opportunities.

Overall, the data indicates that conditional voting was the modal outcome, that video was the more frequently used pathway, that a relatively small number of reasons (particularly Reasons 10, 4 and 7) accounted for the majority of the articulated justifications, and that threats/opportunities were dominated by Category B, followed by Category E.

Discussion

The primary objective of this survey was for the first time to systematically capture the views of individuals living with atypical haemolytic uraemic syndrome (aHUS) regarding a proposed change in disease nomenclature to complement mediated thrombotic microangiopathy, cTMA and others. Specifically, the survey sought to quantify voting pathways (For, Against, Conditional, or Undecided) stratified by communication route (video or email), to categorise the reasons underpinning those positions, and to identify the principal threats and opportunities perceived by respondents in relation to any renaming process.

The findings indicate that conditional responses were the modal outcome (51%), followed by against (32%), with only a single response – for (2%) and 15% remaining undecided. Video was the predominant route (62%), and a limited set of reasons (particularly Reasons 10, 4 and 7) together with Category B threats accounted for the majority of articulated concerns.

The approach adopted—direct solicitation of patient responses via two accessible routes, followed by structured coding of free-text reasons and threats/opportunities—possesses face validity as a pragmatic method for eliciting lived experience in a rare-disease population. The response set (n = 63) and consistency between the voting, reasons and threats/opportunities tables strengthen confidence in the coherence of the data. Nonetheless, generalisation beyond the surveyed cohort must be approached with caution. The sample size, while meaningful for a rare condition, remains modest; self-selection bias cannot be excluded; and the demographic, geographic and clinical characteristics of respondents were not fully characterised in the available tables. Consequently, the results should be regarded as indicative of the views of an engaged subset of the aHUS community rather than definitive for the global population.

The modest modality differences observed here also resonate with recent experimental evidence on communication format which conducted large-scale randomised experiments comparing political video messages with text transcripts and found that while video enhances perceived credibility ("seeing is believing"), its persuasive advantage on attitudes and behavioural intentions is minimal.[5]

Other disease name-change efforts highlight differing approaches to patient views. The shift from "primary biliary cirrhosis" to "primary biliary cholangitis" is the clearest recent example. Patient groups in the UK, Germany, US and Canada surveyed over 1,000 people, showed the stigmatising and inaccurate implications of "cirrhosis," and presented findings at an international meeting. Expert societies (EASL, AASLD and others) then endorsed the change while keeping the acronym PBC, balancing accuracy with patient needs.[6,7] There, patient advocacy shaped the nomenclature from the start. By contrast, the National Kidney Foundation Working Group on aHUS nomenclature involved only a few patient representatives late on, and patients have reported feeling excluded from the three-year process.[8]

Those proposing a change in aHUS nomenclature should therefore interpret the present findings as a clear signal that unconditional support is minimal and that the majority of respondents either oppose the change outright or will accept it only under defined conditions. The dominant reasons and the prominence of Category B Threat suggests that concerns centre on continuity of identity, access to existing therapies and regulatory recognition, risk of diagnostic confusion, and the practical burden of transition.

A constructive response would begin with transparent acknowledgement of these concerns, followed by structured dialogue rather than unilateral implementation. The Working Group itself has recognised patient reluctance as a potential barrier and has indicated that involvement in the process and demonstrable benefits (for example, improved diagnostic precision or treatment access- precision medicine) could mitigate resistance. [3]

Going forward, any transition would require a carefully sequenced programme of work[9]. Essential elements include:

- formal, iterative consultation with patient organisations and individual patients before final nomenclature decisions;
- dual-coding periods during which both the legacy term "aHUS" and any new descriptors remain valid for clinical, regulatory and reimbursement purposes;
- updating of product labelling, clinical guidelines, registries and ICD coding in coordinated fashion;
- development of plain-language educational materials explaining the rationale, the mapping from old to new terms, and safeguards for ongoing access to complement inhibitors; and
- monitoring of unintended consequences on diagnosis, insurance coverage and research cohort integrity. Without such measures, the risk of fragmentation and patient disengagement is substantial.

The World Health Organization, through its custodianship of the International Classification of Diseases (ICD), ultimately determines the official statistical nomenclature. ICD revision processes solicit broad technical input and, in the development of ICD-11, received contributions from more than 270 institutions that included patients among other stakeholders. However, WHO's formal criteria for disease naming—particularly its 2015 best-practice guidance for new human infectious diseases—prioritise scientific accuracy, avoidance of stigma, and utility for surveillance and public health rather than majority patient preference. The 2015 WHO Best Practices for the Naming of New Human Infectious Diseases focuses on principles for new names and does not itself prescribe dual naming, but operational practice consistently favours a transitional dual-name phase to minimise distruption.[10.]

For established rare-disease terms such as aHUS, any revision would typically proceed via expert proposal, national adaptation and subsequent incorporation into the ICD framework; patient opinion is therefore advisory rather than determinative.

Historical precedents show that proposed disease name changes are frequently delayed, only partially adopted, or abandoned when they risk disrupting established clinical communication, literature continuity, or stakeholder consensus. For example, the 2016 MDS Task Force proposal to replace numbered genetic loci for movement disorders with a gene- and phenotype-based system achieved only about 17% uptake in subsequent literature, largely because of concerns over subjectivity, increased nomenclature variability, and the entrenched utility of the older system.[11]

Similarly, the 2024 reclassification of Candida auris to Candidozyma auris met resistance on grounds of prematurity, limited supporting data, and the priority of nomenclature stability for surveillance and clinical practice.[10] Broader campaigns to eliminate medical eponyms have likewise stalled for many conditions due to the practical burdens of updating databases, guidelines and coding systems, alongside recognition of medical tradition.[12]

These cases underscore that even scientifically motivated re-naming rarely succeed without early, structured patient and clinician engagement, dual-naming transition periods, and demonstrable safeguards for continuity of identity, diagnosis and access to care—precisely the contingencies highlighted by aHUS respondents in the present consultation.

Additionally, aHUS is a rare and life-threatening condition that often presents as a medical emergency requiring rapid diagnosis and urgent treatment[13] (e.g., complement inhibitors such as eculizumab), a name change carries greater practical risks than for a non-acute or well-established chronic condition. These risks centre on delayed care, disrupted access to therapy, communication failures, and administrative barriers during the critical early window when organ damage (especially kidney) can progress quickly.

If there is a determination to continue with formally reframing aHUS nomenclature patients and patient organisations should continue to document and communicate their collective positions through formal surveys, position statements and direct engagement with the National Kidney Foundation Working Group, regulatory agencies and WHO ICD revision channels. Maintaining clear records of current diagnoses, treatment regimens and insurance authorisations will be essential during any transitional period. Active participation in co-design of educational materials and dual-coding protocols will help ensure that any eventual change serves, rather than disadvantages, the people who live with the condition.

Informal clinician/researcher normalisation of the term cTMA as happened with normalising the unofficial term aHUS, will accelerates scientific precision but leave existing patients exposed to administrative, access, and identity frictions, while future patients may face diagnostic and support inconsistency within a created two-tier environment. An official route, though slower, systematically protects both groups through dual validity, coordinated systems updates, education, and monitoring—reducing the substantial risk of fragmentation that the Working Group and patient communities have highlighted.[3]

Several limitations should be noted. The sample of 63 responses, while informative, is small and may not represent the full spectrum of the international aHUS community. Self-selection and the dual-route design introduce potential bias toward more digitally engaged or opinionated individuals. The coding of reasons and threats/opportunities, although systematic, necessarily involved interpretive judgement. Demographic, clinical and geographic variables were not used for stratified analysis, limiting assessment of diverse views. Finally, the survey captures attitudes at a single time point; views may evolve as nomenclature discussions progress.

Conclusion

This first structured consultation of aHUS patients and carers on the proposed shift from a symptom-based to a mechanism-based name (cTMA) found predominantly conditional support 32 (51%) or against 20 (32%), with negligible unconditional endorsement. Respondents highlighted practical threats—loss of a familiar name, risks to treatment entitlement and insurance, diagnostic confusion, and community fragmentation—far more than theoretical opportunities. Understanding these perspectives can help bridge differences between proposers and those affected. A transitional composite name retaining aHUS identity, dual-coding periods, coordinated updates to guidelines, registries and coding systems, and sustained multi-stakeholder dialogue are recommended. Further work by patients, organisations and clinical bodies remains essential to prepare for any change while safeguarding continuity of care and community identity.

Appendix A Reasons Coded

	Reason
1	Could confuse doctors more than they are and misdiagnose.
2	Do not know enough of what is planned.
3	Concern about current patient platforms becoming invisible to new patients
4	Risk of losing entitlement to complement treatment (e.g. insurance)
5	Loss or no confidence in managing the major change proposed
6	Worry that division will risk access to research funds
7	Evolve but preserve aHUS continuity for awareness and care access,
8	Diverse names could break existing community cohesion.
9	Name loss will cause confusion for those with idiopathic aHUS.
10	Loss of current name which is familiar.
11	Is science advanced enough to make accurate categorisations (secondaries).
12	Wrong priority should focus on speeding up diagnosis.
13	Needed for tailored care.
14	Can create greater clarity for patients .
15	No reason given.

Appendix B Threats and Opportunities Coded

	Threats and opportunities	Reasons included
A	Concern about the capability of front line to fully understand the change (T)	1
B	Loss of a familiar name (T)	7,10
C	Loss or division of a visible patient community (T)	3.8
D	Concern about ability to manage a project of this scale (T)	2.5
E	Risks to patient management (T)	4.9,11
F	Loss of research funds (T)	6
G	Tackling wrong priority (T)	12
H	Tailored Care (O)	13
I	Greater clarity for patients (O)	14
	None	

T= Threat O= Opportunity

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Ethics Approval: As it was a non-interventional online survey, no ethics approval was necessary. Participants consented by volunteering to participate in an awareness video or writing to aHUS alliance Global Action or to the authors. No general views expressed online were included in the survey without permission.

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