Stroke

SPECIAL REPORT

International Position Paper on Outcome Selection After Aneurysmal Subarachnoid Hemorrhage

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BACKGROUND: The health outcomes currently reported in aneurysmal subarachnoid hemorrhage (aSAH) research lack consistency and do not sufficiently reflect what is important to people most affected. The objective of this article was to establish consensus on the aspects of health (domains) clinicians and researchers should measure in aSAH research.

METHODS: Informed by 2 international prioritizing surveys (involving 239 participants from over 25 countries and 6 continents), we used established consensus methodology in a hybrid in-person/online consensus meeting to establish which domains of health researchers should measure in aSAH research. Sixty-nine participants with lived experience with aSAH (35%), clinical and research leaders (62%), or from aSAH-related charity (3%) took part. International multidisciplinary working groups established consensus definitions for each domain.

RESULTS: Consensus (>70% endorsement) was sought on a proposed group of 6 domains of health, and failing that, each domain individually. The 6 domains which reached consensus and were formally defined are (1) health-related quality of life, (2) survival, (3) cognition and executive function, (4) functional outcome, (5) delayed cerebral ischemia and cerebral infarction, and (6) rebleeding and aneurysm obliteration.

CONCLUSIONS: This International Position Statement reports the consensus process undertaken and the core domain set established to guide the choice of outcomes for evaluating new treatments for aSAH. It will ultimately help shape the future aSAH research agenda.

GRAPHIC ABSTRACT: A graphic abstract is available for this article.

Key Words: consensus ■ ischemia ■ quality of life ■ stroke ■ subarachnoid hemorrhage

Aneurysmal subarachnoid hemorrhage (aSAH) is an acute neurological emergency caused by the rupture of an aneurysm.[1] Up to a third of people who experience an aSAH die within days after the initial bleed, and most survivors are left with long-term challenges, such as functional limitations, cognitive dysfunction, behavior impairments, changes in mood, anxiety, and altered quality of life.[2–4]

Our systematic review of 129 published trials in aSAH identified 285 unique reported outcome measures used

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to evaluate different treatments for aSAH, with most being acute, pathophysiological-based surrogate measures (eg, imaging results or blood tests).[5] Although patient-centered outcomes such as survival (reported in 65% of studies) and ordinal scales of function (77% of studies) were frequently reported, outcomes such as health-related quality of life, cognition, and measures of mood were reported in <10% of studies.[5] Even when a high proportion of studies reported a similar domain (where domain is defined as a specific health aspect, such as pain or mobility), researchers often used different measurement instruments and time points. The high degree of variability in both type and measurement of outcomes makes comparing different treatments and performing systematic reviews of the literature challenging or even impossible.

To improve outcome selection in aSAH research, we established a collaborative partnership among people with aSAH lived experience, healthcare providers, and researchers (collectively referred to as partner groups). We began by evaluating whether the health domains identified in existing systematic reviews were aligned with those considered important by this diverse group of invested parties. Through qualitative interviews and a working group with representation from clinical, research, and lived experience experts, we generated an extensive list of candidate domains.[6] These domains were then prioritized through 2 international surveys involving 239 participants from over 25 countries and 6 continents, with lived experience participants comprising the largest group (53%).[7,8] To comprehensively explore domain prioritization, the survey followed different approaches. The survey results indicated that traditionally underreported domains, such as health-related quality of life and cognition, were among those most highly prioritized by respondents.

Informed by this previous work, we have embarked on establishing a core outcome set (COS) for aSAH to address the mismatch of domains reported in current aSAH research[5] and those prioritized by participants in both surveys.[7,8] A COS is a consensus-derived, limited set (core) of outcome domains and measurement instruments recommended to be assessed in studies of a specific area of health care.[9] It is a widely recognized and established method for improving the consistency of outcome selection, enabling better comparison and aggregation of studies, and ensuring that the outcomes reported in clinical trials are relevant to all invested parties.[10] The methodology for development of COS has been well described by groups such as the OMERACT consortium (Outcome Measures in Rheumatology).[11,12]

Establishing core domains (any measurable aspect of health) for aSAH research and consensus on their definitions are critical steps in developing a COS.[13] This International Position Paper details what aspects of health are most important to report after aSAH and how they are defined.

METHODS

The authors declare that all supporting data are available within the article (and its Supplemental Material; Tables S1 through S6).

Study Design and Setting

To establish the core domains for SAH, in accordance with OMERACT principles, we conducted a consensus workshop with a hybrid in-person and online format using Zoom Webinar Software (San Jose, CA: Zoom Video Communications, Inc) with breakout rooms enabled.[14] The coordinating committee comprised researchers, clinicians, and those with lived experience (S.W.E., C.R.A., M.L.M., J.P., B.S.). To facilitate participation of world leaders in clinical and aSAH research, the workshop was endorsed by and held in conjunction with the International Subarachnoid Hemorrhage Conference that took place on June 16, 2023 at Duke University, NC.

Workshop Participants

We approached people with lived experience of aSAH (patients, carers, or family members) through the Brain Aneurysm Foundation and from mailing lists of people who had previously taken part in our workshops or surveys.[7,8,15] We contacted health care professionals and researchers who had been participants in our previous research, as well as International Subarachnoid Hemorrhage Conference participants. Participants registered their interest by completing an online form via Survey Monkey (San Mateo, CA: Momentive AI). As was the case with our previous consensus meeting (Amsterdam 2019)[6] no informed consent was required as participants were all equal partners contributing to the discussion and voting, and were not research participants. Only demographic data were collected from workshop participants. The background survey work that informed this meeting had ethical approval from the Ottawa Health Science Network Research Ethics Board (Reference 20190312-01H) and by Northern Sydney Local Health District Reference: 2020/ETH03188.

Before the meeting, participants received and reviewed online instructional/informational videos and a frequently asked questions sheet (Supplemental Appendices E and F). The materials included an overview of the aSAH COS project, including current work to date and the workshop purpose.

Candidate Domain Selection and Core Domain Set Proposal

The methods for establishing the critical component of a COS—the core domain set—are well described elsewhere.[11,14] In preparation for the workshop, the coordinating committee compiled a candidate domain list from the top-ranking domains from previously published surveys (Supplemental Appendix A) and proposed a core domain set.[7,8] We aimed to achieve consensus on a limited number of domains to avoid overburdening future clinical trials. We endeavored to include domains from 4 core areas (Life Impact, Pathophysiological manifestation, Resource Use, and Death/Lifespan).[12] Domains were integrated or simplified where overlap between domains existed or in instances where separate domains represented a continuum of the same phenomenon. For example, we combined "Death—overall," "Being alive (survival) 3 months after the subarachnoid hemorrhage," and "Being discharged from hospital alive" into the singular domain survival.

We defined core domains as those considered critically important and essential to report. These were split into 2 types: those required for all trials and those required in specific circumstances (such as certain manifestations of disease or certain types of interventions). Recommended domains were defined as those domains that are important for certain types of trials but not necessary for all. Finally, we defined domains requiring further research as those that require more investigation before they can be considered as core or recommended.

Workshop Process—Establishing the Core Domain Set

Members of the study team, including our lived experience research partner (M.L.M.), introduced themselves. After a brief presentation summarizing the background work leading up to and informing the consensus meeting,[5,7,8,15] workshop participants learned about the process for selecting candidate domains and the proposed core domain set (see above).

Workshop participants then reviewed and discussed the proposed core domain sets. Discussion occurred in small breakout groups of 4 to 9 participants (either in-person or online), facilitated by 1 of 10 facilitators who had previously completed OMERACT training.[16] After 45 minutes of structured small group review, a spokesperson from each group summarized their respective reviews in a plenary discussion. A member of the coordinating committee (C.R.A.) facilitated the plenary session and guided alterations to the proposed core domain set.

At the conclusion of the plenary discussion, all participants voted on the finalized candidate core domain set using an online voting platform (Slido.com, Bratislava, Slovakia: Cisco Systems, Inc). For the core domain set to be adopted, consensus was required. Consistent with OMERACT guidelines,[14] consensus required a vote of >70% in both the lived experience and health care provider/researcher cohorts. Several voting rounds were possible. The candidate core domain set was first voted on in its entirety. In the absence of consensus, each individual candidate domain was then voted on for inclusion (or not) in a revised core domain set. Finally, a revised core domain set was voted on for adoption through consensus. Workshop participants were asked to identify which group they belonged to when voting. No other information about them was recorded.

Establishing Core Domain Definitions

With the core domain set established, workshop participants were again allocated to small groups (in person) and virtual groups (online) and were invited to discuss proposed definitions for each core domain. Each small group received an initial draft of the domain definition that the organizing committee created and detailed using an OMERACT template Domain Definition Report.[14] The draft definitions were informed by literature reviews with sources, alternative definitions, and the background to the domain selection (eg, where it ranked in the 2 international consensus surveys), all detailed in the report. Each small group discussed the definitions of 2 domains before presenting their findings in the plenary discussion. For domains in which definitions were not adopted in the plenary, working groups were formed to resolve the definitions. The composition of the working groups was based on ensuring diversity according to a participant's geographic location and status as someone with lived experience, a healthcare professional or researcher, or from industry, charity, or government. One study team member (G.F.) participated in all working groups to provide participants with the background to the previous work, oversee a consistent process across groups, and ensure the focus of the group remained on the domain definition. Working groups were first provided with the original definition presented at the workshop (Supplemental Appendix B) and a qualitative summary of workshop discussions. Generally, an initial meeting amended the definition and ended when an agreement was reached. The revised definition was then circulated via email to all group members. This revised definition was the focus of the second meeting. After a second revision, comments were invited via email. When no further substantive comments were put forward, a vote was held on whether the definition was endorsed by the majority of working group participants.

RESULTS

Workshop Participants

There were 88 registered participants, and 69 attended the meeting either in person (59%) or online (41%). A breakdown of participants by expertise, sex, and geographic representation is presented in Supplemental Appendix C. Thirty-seven participants (54%) were women, 24 (35%) had lived experience, 2 (3%) were from an aSAH charity, and the remaining 43 (62%) were health care providers and researchers. Attendees were drawn from 13 different countries (Canada [12%], United States [68%], Australia [6%], Switzerland [3%], the Netherlands [1%], Germany [3%], Finland [1%], Spain [1%], United Kingdom [3%], India [1%], China [1%], South Korea [4%], and Singapore [1%]) across 4 continents. Most participants (97%) were from high-income countries.

Candidate Domains

The domains from the previously published surveys are integrated in Table 1.[7,8] Collectively, they formed 6 core domains, which were proposed as a candidate core domain set at the workshop. Emotions or mood were added for discussion as an important but optional domain based on the results from 1 published survey and feedback from lived experience partners.[7] We also added the resource use domains for discussion to acknowledge the OMERACT guidelines that recommend the inclusion of resource use domains (Table 2).[14] A description of the demographics of the survey participants is included in Supplemental Appendix C.

Core Domain Set Discussion and Consensus

During the small group and plenary discussions, 9 candidate domains for inclusion in a core domain set were

Table 1. Integrated Domains From the Previously Published Surveys in the Core Domain Set

Proposed core domain	Domain name used in source survey	Source survey* (ranking)
Cognition and executive function	Cognition and executive function	B (1)
	An assessment of memory and cognitive function	A (6)
Functional outcomes and activities of daily living	The ability to independently manage basic needs such as toileting, feeding, bathing, and getting dressed	A (2)
	A measure of function or return to baseline function	A (3)
	Functional outcomes, including the ability to walk	B (4)
	The ability to independently manage instrumental activities of daily living, such as managing finances, shopping, preparing food, and doing laundry	A (5)
	The ability to walk independently	A (7)
	The BADLs, the ability to provide basic self-care	B (8)
Overall HRQoL	The overall HRQoL as reported by the SAH survivor	A (1); B (6)
Survival†	Being alive (survival) 3 mo after SAH	A (8)
Delayed cerebral ischemia or cerebral infarction	Delayed cerebral ischemia or cerebral infarction	A (4)
	Cerebral infarction	B (3)
	Delayed cerebral ischemia	B (5)
Aneurysm obliteration and rebleeding	Aneurysm obliteration	B (2)
	A subsequent bleed related to the aneurysm (rebleeding)	A (9)

BADL indicates basic activities of daily living; HRQoL, health-related quality of life; and SAH, subarachnoid hemorrhage.

*Two source International Consensus surveys were integrated: A: International Q-Sort Survey[7]; B: International Delphi Survey.[8]

†Death must be reported in any clinical trial of an investigational medicinal product.

discussed (the original 6 proposed, and 3 additions). The workshop discussion of the 9 domains centered around relative importance, foreseeable challenges in adoption, and domain scope. Table 2 contains a domain summary.

After 2 breakout sessions and full workshop discussions, consensus in favor of the proposed core domain set (Table 3) was sought from all workshop attendees. Of the attendees present and online, 60 participated in the vote on the proposed SAH core domain set with 88% overall endorsing the proposed core domains and their classification as presented (Table 3). Support came from 18 (75%) of the lived experience group and 35 (74%) other key partners (which included researchers, health care providers, and charity). Based on COS development standards, consensus was achieved, and no further voting took place.[13]

Core Domain Definitions

Of the 6 core domains in the endorsed aSAH core domain set, definition consensus was achieved for 2 domains at the workshop (Table 4). The group reached consensus on delayed cerebral ischemia and cerebral infarction using published international consensus definitions of Vergouwen et al.[13] Also adopted was the proposed definition of survival, defined as being alive at a given time point after subarachnoid hemorrhage. A summary from the 4 working groups created to define the remaining core domains follows, and Table 4 includes the resulting definitions (additional details in Supplemental Appendix D).

Cognition and Executive Function Working Group

This working group comprised a team lead and 12 additional members. Participants from 3 different continents included those with lived experience (n=6), clinicians/researchers (n=6), and 1 from a charitable organization. There were 2 meetings with 8 participants taking part in the first and 6 participants in the second. All 13 group members voted unanimously on the final definition presented in Table 4.

Health-Related Quality of Life Working Group

Twelve people from 3 different continents comprised this working group, which was led by a lived experience member. Eight people participated in the 2 meetings conducted, and 10 (4 with lived experience and 6 healthcare professionals/researchers) voted unanimously to endorse the definition (Table 4).

Functional Outcomes Working Group

Twelve people were invited to join this group, which was led by a clinician-researcher. Participants were from 4 different continents and included those with lived experience (n=5) and clinicians/researchers (n=7). Of those invited, 9 participated, and 1 additional member provided comments via email across 4 meetings. All 10 people (4 with lived experience and 6 healthcare professionals/researchers) who voted on the final definition endorsed it unanimously (Table 4).

Table 2. Summary of Workshop Discussion on Candidate Domains

Proposed core domain	Domain origin	Proposed domain classification	Workshop discussion points
Cognition and executive function	Survey results	Core domain in all trials	Relative importance: Specific aspects of cognition. Challenges: The difficulty in measuring change from premorbid function in an acute condition like aSAH.
Functional outcomes and activities of daily living	Survey results	Core domain in all trials	Relative importance: How to characterize this specifically from an aSAH perspective was considered important. Domain scope: Daily functioning, as well as social and employment functions, was emphasized.
Overall health-related quality of life	Survey results	Core domain in all trials	Domain scope: The health-related aspect of QoL was considered relevant, as well as the importance of this over a longer time frame.
Survival	Survey results	Core domain in all trials	Domain scope: Time point for measurement is a key determinant.
Delayed cerebral ischemia or cerebral infarction	Survey results	Core domain in specific circumstances	Domain scope: More important to the health care professionals, and the discussion points were more technical in nature.
Rebleeding and aneurysm obliteration	Survey results	Core domain in specific circumstances	Domain scope: The definition of obliteration was a focus of the discussions; Non-HCP participants felt that this was important but were less concerned about the technical and definitional discussions.
Emotions or mood	Lived experience partner feedback	Recommended domain	Relative importance: Lived experience participants expressed strong support for the inclusion of this domain.
Indirect and direct costs of treatment	COS development standards requirements for resource use domains	Requiring further research	Relative importance: The overall costs of treatment were considered very important by some lived experience participants. Challenges: Recommended as requiring further research.
Availability and access to treatments	COS development standards requirements for resource use domains	Requiring further research	Relative importance: Access to treatment was considered very important by a subset of participants. Challenges: Recommended as requiring further research.

aSAH indicates aneurysmal subarachnoid hemorrhage; COS, core outcome set; HCP, healthcare professional; and QoL, quality of life.

Rebleeding and Aneurysm Obliteration Working Group

Eleven people across 4 different continents were invited to join this group. A clinician-researcher led the group, which consisted of those with lived experience (n=4) and clinician/researchers (n=8). At the initial meeting, the working group participants elected to seek external opinion from 3 experts to help refine the definitions. The definitions were then circulated by email between workshop participants, with steering committee opinions also sought. A final definition was then proposed based on the advice received and voted on by 10 (2 with lived experience, 7 healthcare professionals/researchers, whereas 1 person did not answer the group identification question) of the working group participants, with the definition endorsed unanimously (Table 4). Given the technical nature of this domain, the group also provided a glossary.[17]

DISCUSSION

Within this article, we explained the process and product of an international consensus meeting to establish and define a core domain set for aSAH. The process involved equal representation of those with lived experience with aSAH and world experts and researchers in the field, with gender balance and representation from 4 continents and 13 countries. Consensus was achieved on 4 health domains (and their definitions) which should be considered core for inclusion in future SAH research: cognition and executive function, health-related quality of life, survival, and functional outcomes. In addition, 2 domains were considered core in specific circumstances (eg, studies focusing on acute management): (1) delayed cerebral ischemia and cerebral infarction, and (2) rebleeding and aneurysm obliteration.

A review of previous work reveals that some outcome measures—including cognition, quality of life, and

Table 3. The Core Domain Set for aSAH Research

Core domain for all aSAH trials	Cognition and executive function
	Functional outcomes and ADLs
	Overall health-related quality of life
	Survival
Core domain in specific circumstances	Delayed cerebral ischemia and cerebral infarction
	Rebleeding and aneurysm obliteration
Recommended domains	Emotions or mood
Domains needing further research	Direct and indirect costs of treatment
	Availability and access to treatments

ADLs indicates activities of daily living; and aSAH, aneurysmal subarachnoid hemorrhage.

Table 4. Definitions for the aSAH Core Domains

Cognitive and executive function
Cognitive and executive functions include the following interrelated processes:
Attention–The ability to focus, shift, divide, or sustain attention on a particular stimulus or task or range of tasks. Memory–the ability to recall in the short or long-term and the recognition of visual and verbal information, be it about experiences (episodic) or meaning (semantic). Executive function–involved in planning, abstract thinking, organization of thoughts, inhibition, conflict monitoring, and multitasking. Perception–includes both auditory and visuospatial ability. Auditory perception includes dealing with crowded places or focusing where there is a lot of background noise. Visuospatial ability is or the aptitude to visually search or scan for information, to draw or recreate visual images, and mentally manipulate objects 2- and 3-dimensional objects Language–the ability to express and be receptive to language through speech, writing, and reading comprehension across any of an individual's languages. Cognitive processing–includes the volume and speed of information processing and motor reaction time.
Health-related quality of life
Health-related quality of life is a term referring to the health aspects of quality of life, which reflects the impact of subarachnoid hemorrhage and its treatment on broad concepts of an individual's physical, psychological, and social functioning and well-being, including any financial impact. It has also been considered to reflect the impact of perceived health on an individual's ability to live a fulfilling and purposeful life.
Functional outcomes
Functional outcomes refer to aspects of general life and day-to-day function that may be impacted because of subarachnoid hemorrhage-related impairments. This can be thought of along a scale from basic activities of daily living, through instrumental activities of daily living and mobility, and onto social, professional, and family life.
Basic abilities Completing activities of daily living or essential to an individual's personal care, such as getting into and out of bed and chairs, dressing, eating, toileting and bathing, and grooming. The ability to walk with or without assistance or the ability to walk independently. Instrumental abilities Completing activities essential to an individual's ability to function autonomously, including cooking, doing laundry, taking care of a home, managing money, shopping, and getting to places beyond walking distance. Social role performance abilities Work, previous role in the household, social, and family life) at any capacity (eg, same workload, reduced workload) The degree to which an individual can return to prehemorrhage baseline function on their journey of recovery.
Survival
Survival is being alive at a given time point after a subarachnoid hemorrhage.
Rebleeding and aneurysm obliteration
Rebleeding: A distinct second instance of bleeding from a cerebral aneurysm (before, during, or after treatment of the aneurysm).
Aneurysm obliteration: Complete angiographic occlusion (eg, clipping, coiling) resulting in elimination of a cerebral aneurysm from cerebral circulation. Glossary Aneurysm: is a bulge in a blood vessel caused by a weakness in the blood vessel wall, usually where it branches. Angiographic: To do with the health of your blood vessels and how blood flows through them. Cerebral: of or relating to the brain. Clipping: A treatment to seal the aneurysm shut using a tiny metal clip that stays permanently clamped on the neck of the aneurysm. Over time, the blood vessel lining will heal along the line where the clip is placed, permanently sealing the aneurysm and preventing it from growing or rupturing in the future. Coiling: A treatment to fill an aneurysm full of tiny platinum coils so blood cannot enter it. This means the aneurysm is sealed off from the main artery, which prevents it from growing or rupturing. Occlusion: the blockage or closing of an opening or blood vessel.
DCI and CI[17]
DCI is "the occurrence of focal neurological impairment (such as hemiparesis, aphasia, apraxia, hemianopia, or neglect), or a decrease of at least 2 points on the Glasgow Coma Scale (either on the total score or on one of its individual components [eye, motor on either side, verbal]). This should last for at least 1 h, is not apparent immediately after aneurysm occlusion, and cannot be attributed to other causes by means of clinical assessment, CT or MRI scanning of the brain, and appropriate laboratory studies."
CI is "The presence of cerebral infarction on CT or MR scan of the brain within 6 wk after SAH, or on the latest CT or MR scan made before death within 6 wk, or proven at autopsy, not present on the CT or MR scan between 24 and 48 h after early aneurysm occlusion, and not attributable to other causes such as surgical clipping or endovascular treatment. Hypodensities on CT imaging resulting from ventricular catheter or intraparenchymal hematoma should not be regarded as cerebral infarctions from DCI."

aSAH indicates aneurysmal subarachnoid hemorrhage; CI, cerebral infarction; CT, computed tomography; DCI, delayed cerebral ischemia; MRI, magnetic resonance imaging; and SAH, subarachnoid hemorrhage.

emotions or mood—are reported infrequently in randomized aSAH studies.[5] Yet, engagement with key partners with a vested interest in aSAH has demonstrated to us that these were the very domains that they felt were among the most important.[7,8] This core domain set addresses the mismatch while reiterating the importance of well-reported measures such as functional outcome and survival.

The nearest comparable work in a neurology context is the stroke standard set that was published in 2015.[18] The stroke standard set used a working group and Delphi process over a much shorter period and with only limited lived experience representation. It explicitly excluded aSAH, recommending a separate process specific to this population. Despite the different methodology, the core domains selected in the stroke standard set show reasonable overlap with those endorsed in the aSAH core domains. This includes the domains of survival, patient-reported cognitive function, mood, mobility, and health-related quality of life. The work presented here also aligns with other efforts to standardize outcome reporting in aSAH research, such as the Common Data Elements, which the National Institute of Neurological Diseases and Stroke sponsors.[19,20] Although the goal of the Common Data Elements work is also to improve clinical trials, data sharing, and analyses, to date, no core outcomes have been established from the 50 outcomes the working group of international experts identified. The aSAH core domains can inform the future iterations of the Common Data Elements project, especially as their identified groupings of outcomes overlap with our core domains (eg, Cognitive Impairment, Health-Related Quality of Life, Disability and Participation Restriction/Return to Work).

A key strength of the current study is the central role played by people with lived aSAH experience. Essential members of the study team are patient research partners who have been influential in the planning, design, and execution of the research program. People with lived experience also took part in generating potential domains during the initial interviews and workshops and have been key contributors to the 2 surveys, where overall they are the largest stakeholder group. People with lived experience of aSAH are the experts of this condition as they live with its consequences every day; thus, when they are engaged in the research process, they broaden the research agenda, and this improves research outcomes.[21,22]

An additional strength of the current research is that it also follows the well-established methodology of the OMERACT consortium.[14] Developed over several decades, this methodology represents the most robust technique for generating consensus around outcome measures.[23] The considered, stepwise approach to achieve a core domain set is not achievable in a short period of time, but this careful approach does engender confidence in the selected domains and assists with subsequent knowledge translation.

Our work is not without limitations. Low- and middle-income countries were underrepresented in this work, potentially affecting its generalizability in these countries. Although representation at this workshop was low, our preceding work, which informed the workshop, included higher representation from regions with a higher proportion of low- and middle-income countries (Africa, South America, the Caribbean, and Central America). In our future work to identify measurements for the core domains, participation from low- and middle-income countries will be crucial to determining the feasibility of using those measures. In addition, although this work may help to inform a COS specific to aSAH, it does not address potential barriers to adopting one.

One such potential barrier to adopting a COS is the additional costs that it might add to conducting research.[24] As is often the case, the aspects of health that matter most to those with lived experience and other invested parties are often the domains that are more challenging to measure. Although it is important to ensure that research is conducted in the most efficient way to maximize impact across the health system, we should not shy away from measuring the outcomes that matter. Part of this goal will be through advances in data collection, and part of this will be in ensuring the measurement instruments selected for the core domains are feasible and efficient.

After establishing what to measure in aSAH, there is still work to be done. Several working parties will evaluate candidate measurement instruments and how well they are able to characterize the core domains before final selection of the measurement instruments and the establishment of a COS in aSAH. This direction aligns with the recommendation from the NINDS Common Data Elements aSAH research group for future work.[20]

CONCLUSIONS

Using a well-established process driven by the participation of patients and other individuals with lived experience of aSAH, we have identified several core patient-centered health domains. These aspects of health should be prioritized in clinical research in this population. These core domains provide guidance to researchers, clinicians, and policy makers on what matters after aSAH.

ARTICLE INFORMATION

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Supplemental Material

Tables S1–S6
Appendices A–E

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