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RESEARCH

What to Measure in Aneurysmal Subarachnoid Haemorrhage Research—An International Delphi Survey

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Abstract

Aneurysmal subarachnoid haemorrhage (aSAH) is a devastating condition with high mortality and morbidity. The outcome measures used in aSAH clinical research vary making it challenging to compare and combine different studies. Additionally, there may be a mismatch between the outcomes prioritized by patients, caregivers, and health care providers and those selected by researchers. We conducted an international, online, multiple round Delphi study to develop consensus on domains (where a domain is a health concept or aspect) prioritized by key stakeholders including those with lived experience of aSAH, health care providers, and researchers, funders, or industry professionals. One hundred seventy-five people participated in the survey, 59% of whom had lived experience of aSAH. Over three rounds, 32 domains reached the consensus threshold pre-defined as 70% of participants rating the domain as being critically important. During the fourth round, participants ranked the importance of each of these 32 domains. The top ten domains ranked highest to lowest were (1) Cognition and executive function, (2) Aneurysm obliteration, (3) Cerebral infarction, (4) Functional outcomes including ability to walk, (5) Delayed cerebral ischemia, (6) The overall quality of life as reported by the SAH survivor, (7) Changes to emotions or mood (including depression), (8) The basic activities of daily living, (9) Vasospasm, and (10) ICU complications. Our findings confirm that there is a mismatch between domains prioritized by stakeholders and outcomes used in clinical research. Our future work aims to address this mismatch through the development of a core outcome set in aSAH research.

Keywords Subarachnoid hemorrhage · Cerebral aneurysm · Patient-important outcomes · Core outcome set

Introduction

Aneurysmal subarachnoid haemorrhage (aSAH) is a form of haemorrhagic stroke that occurs due to the rupture of an abnormal blood vessel in the brain. It is distinct from other forms of stroke in terms of the population it affects (younger and more likely to be female), its pathophysiology, and long-term sequelae [1, 2]. There is a mortality rate of 35% (range 20–67%) [3] and of those who do survive, most are left with long-term morbidity [4, 5].

A lack of consistency in the outcome measures used to evaluate aSAH treatments directly impacts researchers' and clinicians' ability to compare and aggregate trial results which, in turn, reduces research efficiency [6]. Over the past 20 years, 285 unique outcomes have been reported in 129 randomized controlled trials involving SAH patients [7]. Multiple definitions and measurement instruments are used to characterize frequently reported domains such as assessment of function (> 75% of included studies) where 10 distinct instruments were used. Patient-reported quality of life measures were rarely reported (< 10% of included studies) but, again, seven different instruments were employed to measure it. Finally, trials measure and report these outcomes at variable time points rendering it difficult to reliably assess recovery [7].

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There are also mismatches in the outcomes used by researchers relative to what is considered important by patients, family, and health care providers [8, 9]. Indeed, studies have shown discrepancies between what those with lived experience of aSAH and health care practitioners consider important when determining the quality of a patient's outcome following aSAH, and between members of different health care specialties themselves [10, 11]. Patient engagement initiatives have emphasized the importance of aligning the priorities of patients, clinicians, and researchers in the promotion of stroke recovery [12, 13].

To address the lack of consistency and help align outcome selection with stakeholder preferences, an international consortium of people with lived experience of aSAH, researchers, and health care professionals is developing a core outcome set (COS) for aSAH [14]. A core outcome set is a limited set of outcome measures that all studies in a particular clinical area are recommended to report [15]. COS development is informed by rigorous methodology developed by the Outcomes in Rheumatology Consortium (OMERACT) and related organizations such as the Core Outcomes Measures in Effectiveness Trials (COMET) initiative [16]. Key to the development of a COS is understanding which measurable aspects of health (referred to as domains) are most important. In this study, consistent with recognized COS development methodologies, we have used an international Delphi survey to build consensus towards a set of core domains in aSAH [17, 18].

Objective

To develop consensus among the various groups with a vested interest (people with lived experience, health care professionals, and researchers, funders, and industry professionals) in which domains should be measured and reported in aSAH research.

Methods

Ethics

Ethical approval for this study was granted by the Ottawa Health Science Network Research Ethics Board (reference: 20210028-01H). These results are reported according to the Equator Checklist for Reporting of Survey Studies (CROSS) [19]. The project to develop a COS in aSAH has been registered with the COMET database [20].

Study Design

We conducted an international, online, Delphi-based questionnaire study with three stakeholder groups (people with lived experience of aSAH [people who had an aSAH and/or their family members]; health care professionals; and a group consisting of funders, researchers, and industry professionals). The Delphi survey was completed using the web-based Delphi Manager (The COMET Initiative, Liverpool UK) and consisted of four rounds. The Delphi technique is a methodological approach for reaching consensus anonymously that provides all participants an opportunity to have an equal voice, while also allowing consideration of how their view aligns with others [17, 21, 22].

Participants

We approached potential participants with lived experience via email through the Brain Aneurysm Foundation. We also posted invitations with moderator approval to private online forums such as the Subarachnoid Haemorrhage Group set up by the Brain and Spine Foundation UK. We identified health care providers through local contacts, national organizations, and international collaborative networks. Eligible health care providers included nurses, physiotherapists, occupational therapists, dieticians, and medical doctors involved in the management of aSAH from acute care to rehabilitation. We also invited funders, researchers, and industry professionals involved in research funding. Given the rarity of this condition, we further identified those with relevant professional or personal experience through snowball sampling, where we asked eligible participants to identify others who may be interested in participating. Through this process, we identified 253 potential participants who were invited via a unique link to an online Survey Monkey (SurveyMonkey Inc., San Mateo, CA, USA., www.surveymonkey.com) form where they provided basic demographic details. Each participant consented to participate upon registration using the web-based Delphi Manager and we informed participants that they could withdraw at any time. After potential participants registered their interest, we sent an introductory email that explained the overall aims of the project and the Delphi survey process (Appendix 1).

Sample Size

Based on previously published COS development we aimed for a sample size of 100–200 participants [23–25].

Candidate Domains

We used a mixed methods approach to generate an initial broad range of candidate domains. This included a literature review on previous outcomes in aSAH research, qualitative interviews with people who have lived experience of aSAH (unpublished), and a multi-stakeholder workshop conducted at the international aSAH research meeting (see Appendix 2 for full domain list) [7, 14, 26]. These domains were classified according to four core areas (pathophysiological manifestations, life impact, resource use, and death) in accordance with the OMERACT process [27]. Members of the research team (CA, SE, JS, MM), including patient partners (MLM, PT, XZ), then removed duplicates and grouped overlapping domains to include 62 domains for rating [28]. During Round 1, participants were also offered the opportunity to suggest any domains missing from the initial 62 and these were added in Round 2.

Data Collection

Consistent with standard practice, in Round 1, participants rated the importance of each domain (on a 9-point Likert-like scale). In Round 2, participants received their Round 1 rating for each domain along with the median rating from Round 1 and the rating distribution across all participants. Participants could then re-rate domains or retain their initial rating. To determine consensus, Delphi Manager software dictates that two groups are needed. We grouped participants into a lived experience group and a combined researcher and health care professional group. Consensus for any domain was achieved when greater than 70% of participants in both groups rated it as critically important (rated as 7–9) and less than 15% of participants rated the same domain as of limited importance (rated as 1–3). The domains that achieved consensus were automatically removed after Rounds 2 and 3 by the Delphi Manager program. In Round 3, participants again received their rating for each remaining domain along with the rating distribution and the median rating for that domain from both groups and were able to re-rate domains if they wished.

To gain further insight into the relative priority of domains considered critically important, we included, a priori, an additional (fourth) ranking Round. This ranking was introduced to aid development of a core domain set given that the large number of identified domains meant it was possible many domains would be endorsed as critically important. In this situation, ranking the domains introduces a mechanism to assess participants' priorities. In this final Round, participants were asked to rank the domains that achieved consensus in Rounds 2 and 3 into their top ten in order of importance. A score of 10 was allocated to the top position with descending scores until the 10th position which scored 1. The summed scores for each individual domain reaching consensus provided an overall ranking based on the highest overall score.

Participants were also able to provide free text comments during Rounds 1 to 3 with the prompt 'Provide feedback' after each domain in each of the three initial Rounds. After Round 4, there was also an opportunity to provide free text with a prompt 'Comments'. A descriptive analysis of the free text entered by participants was performed using a single coder. The survey was initiated on 11 January 2022.

Results

Participant Characteristics

Figure 1 summarizes participant characteristics. From the 253 potential participants identified, 175 (70%) registered in the survey. Of the registered participants, 104 (59%) identified primarily as belonging to the aSAH survivor or family stakeholder group, 13 as researchers or industry (7%), and 58 (33%) as health care providers (see Appendix 3). Most (65%) respondents self-identified as women and the most common age range was 46–55 (31%). Respondents from 25 different countries and all regions of the world took part (Fig. 1).

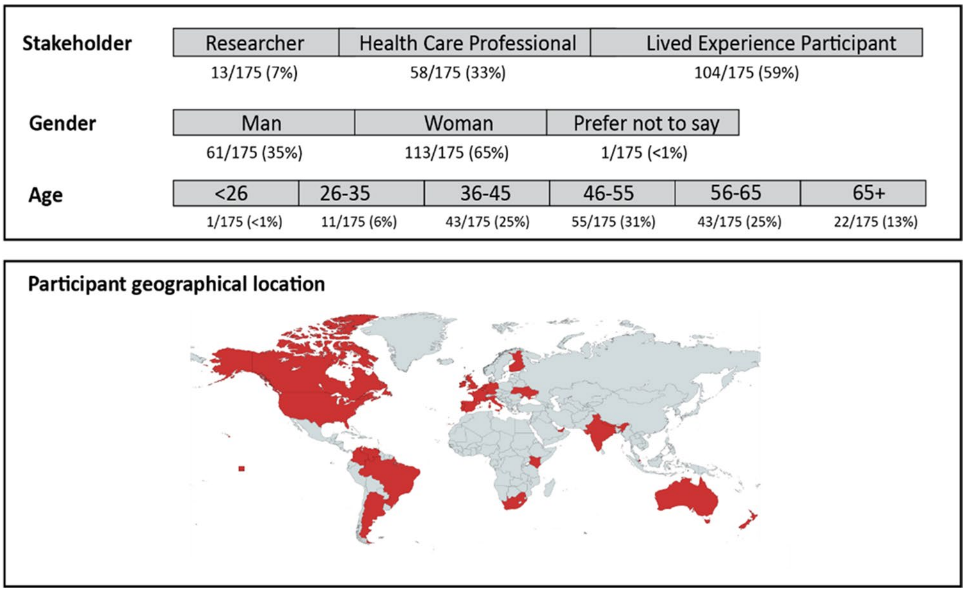

Fig. 1 Participant demographics and depiction of the countries they lived in

Stakeholder	Researcher	Health Care Professional	Lived Experience Participant
	13/175 (7%)	58/175 (33%)	104/175 (59%)

Gender	Man	Woman	Prefer not to say
	61/175 (35%)	113/175 (65%)	1/175 (<1%)

Age	<26	26-35	36-45	46-55	56-65	65+
	1/175 (<1%)	11/175 (6%)	43/175 (25%)	55/175 (31%)	43/175 (25%)	22/175 (13%)

Round 1

Round 1 was open from 11 January 2022 until 14 February 2022. It was completed by 154 (87.5%) of the registered participants (see Fig. 2). The mean scores and the percentage of participants rating each of the 62 domains as critical (7–9) for Round 1 are provided in Appendix 4. Eleven additional domains suggested by participants were added to Round 2 for ranking (see Fig. 3) and are listed in Appendix 5.

Round 2

Round 2 was open from 15 February 2022 until 28 March 2022. It was completed by 127 participants from the 154 who completed Round 1 (82.5%, Fig. 2). Of the 73 included domains, 25 met the pre-defined consensus criteria and progressed directly to the ranking round (see Fig. 3). The full results from this round are in Appendix 6.

Round 3

Round 3 was open from 29 March 2022 until 25 April 2022. It was completed by 124 participants from the 154 that completed either the first or second rounds (80.5%, Fig. 2). This represented an overall response rate of 70.8% (124 of 175 registered participants). Participants rated the 48 remaining domains that had not yet reached consensus (Appendix 7). An additional 7 domains reached consensus after the third round. The full list of domains that achieved consensus is listed in Fig. 4.

Round 4 (Ranking Round)

Round 4 was open from 26 April 2022 until 23 May 2022. Participants ranked their top ten domains from the 32 domains that reached consensus. The summary results for Round 4 are presented in Table 1. Cognitive and executive function was the highest ranked domain overall and was also ranked in the top two by each stakeholder group. Delayed cerebral ischemia was the highest ranked domain for health care professionals whereas those with lived experience ranked this domain 24th. Measures of survival had the three highest mean Delphi scores after round 2 but, when ranked overall, they rated 14th, 23rd, and 32nd.

Key Themes in Comments by Participants Within Rated Domains

During the domain rating exercise, 13/175 participants made comments, often on multiple domains: 8/104 from the lived experience group, 1/13 from the researcher group, and 4/58 from the health care professional group.

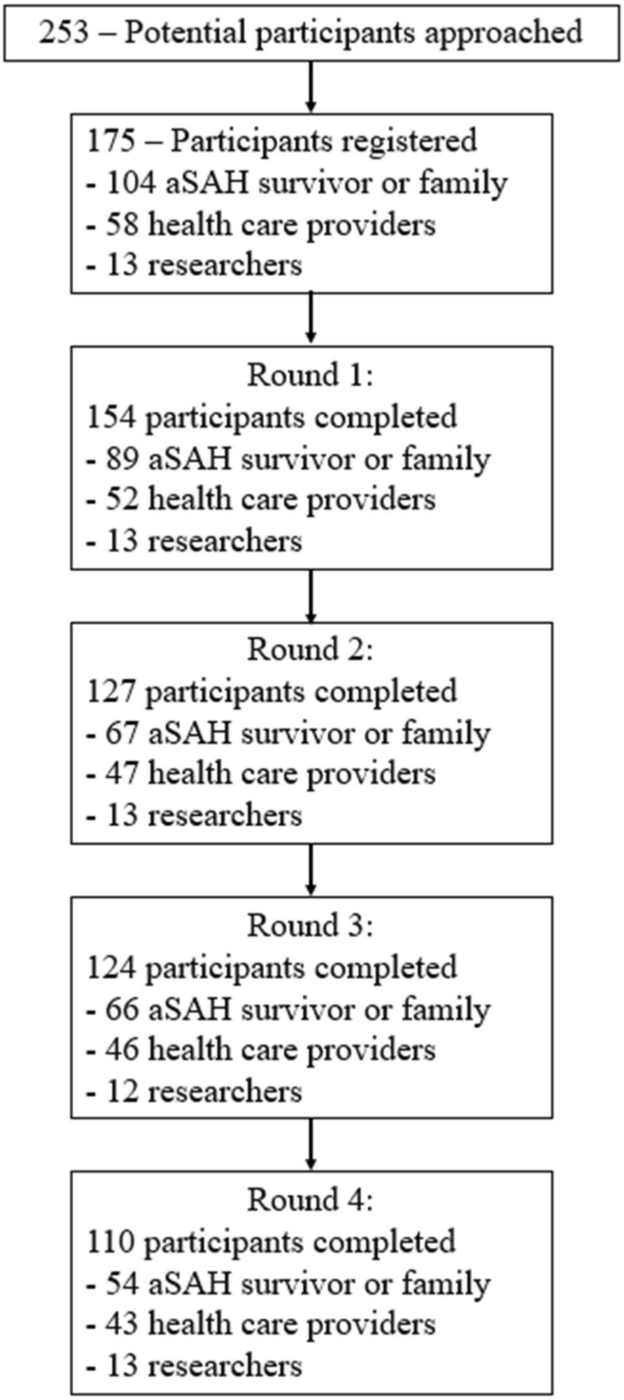

Fig. 2 A flowchart displaying the number of participants who participated in each round of the Delphi survey

> Domain Theme 1: Situating mortality: For the survival domains, there were three comments including ‘if you die all the rest are not important’ and ‘Mortality is obvi-

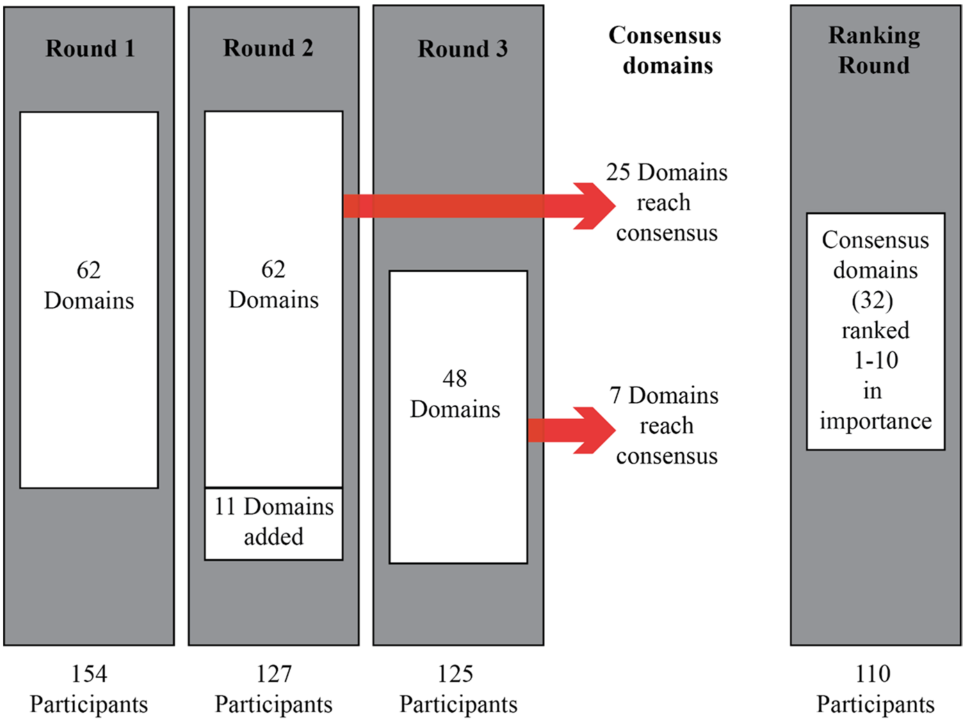

Fig. 3 The four voting Rounds undertaken in this survey with the number of participants completing each round from a maximum of 175 registered participants. Note: After Round 1, 11 additional domains suggested by participants were added. After Round 2, 25 domains reached consensus and progressed to the ranking round. A further 7 domains reached consensus after Round 3 and also progressed to the ranking round. The 32 consensus domains that were ranked are illustrated in Fig. 4

ously a crucial outcome, however not as important as functional/cognitive outcomes'.

Domain Theme 2: Clarifying views about resources: In the resource domains, 5 participants made comments. One participant referred to issues with financial incentives in respective health systems such as 'there is a financial reason for patients rehabilitation length of stay'. One participant expressed uncertainty with respect to the overall measure of quality-of-care domain commenting 'Guideline concordance? Patient satisfaction? My response could be influenced in either direction depending on which'. For the discharge destination after hospital a participant commented that '[the] ultimate destination is more important than initial destination following discharge'.

Domain Theme 3: Qualifying views about specific pathophysiological manifestations: There were comments from 10 participants with respect to pathophysiological domains. With respect to aneurysm obliteration, one participant commented 'this is an early and important milestone. However, the aneurysm does not necessarily have to be COMPLETELY obliterated. It is not uncommon for there to be a small residual component to the aneurysm and for it to be still secure'. Another commented 'cerebral infarction is irrelevant as the sole outcome parameter if there are no symptoms or function restrictions after rehab'. One participant wrote 'Like… how important are vasospasms. Well; my wife had them. It was terrible. But they controlled them. So, of course you don't want them; but in the end if she had them and was ok upon discharge; who cares if she had them as part of the recovery/treatment process.'

Domain Theme 4: Clarifying perspectives on life impacts: With respect to life impact domains, there were comments from 3 participants. One respondent commented after the memory changes domain 'the ability to process information is also important. I can no longer read a book'. Following scoring of the anxiety and/or PTSD domain a participant commented 'I expect perspective of clinicians and patients may differ here. Like all the things listed here it is important. However, I'm not sure PTSD is a bigger problem with SAH than with other critical care conditions in general!'. One participant commented on the quality of life as reported by the survivor domain with the following 'Getting others to understand that I may look the same as before and on surface seem fine; but there is lots going on that can't be seen'.

Key Themes in Comments by Participants at End of Survey

In the free text section at the conclusion of the survey, 50/175 participants provided comments related to the survey: 39/104 from the lived experience group, 3/13 from the researcher group, and 8/58 from the health care professional group. Two main themes emerged from those responses:

Overall Comments Theme 1: Delphi process and interface: Sixteen participants conveyed their appreciation for the

Life Impact Domains

Cognition and Executive Function
Functional outcomes including ability to walk
The overall quality of life as reported by the SAH survivor
Changes to emotions or mood (including depression)
The basic activities of daily living (BADLs); ability to provide basic self care
Instrumental activities of daily living (IADLs) which enable people to live independently
Verbal communication
The ability to maintain concentration or focus
Memory changes
Return to previous role/returning to baseline
Decision-making ability (e.g. speed)
Caregiver and family support for person with aneurysm; including emotional support
Taking care of children
Understanding what is happening/what will happen; information and education for patients and their families
Impact on the physical and mental health of family and caregivers

Pathophysiological Domains

Aneurysm obliteration
Cerebral infarction
Delayed cerebral ischemia
Vasospasm
ICU Complications
Rebleeding
Early brain injury
Alteration of consciousness
Recanulization; Recurrence; or Retreatment
Physical health of person with aneurysm

Survival Domains

Death – overall
Survival to a specific time point such as three months after the initial SAH
Survival to hospital discharge

Resource Use Domains

A measure of the overall quality of care
Overall financial impact on the patient or family
Destination after discharge from hospital
Availability and access to any type of therapy

Fig. 4 The 32 domains considered to be critically important by survey participants categorized according to the OMERACT process [15]

opportunity to participate in the Delphi process. Generally, the comments were favourable regarding the experience with one participant commenting '[The Delphi process] shows how sometimes the caregivers, healthcare providers and researchers share priorities and the areas in which they differ. Fascinating.' Several respondents expressed difficulty with the survey interface with comments such as '[I] struggled to see the font used in completion' and from another respondent 'I used my phone to answer the survey and had a hard time reading it'. One participant indicated that 'their level of comprehension has impaired my response'.

Overall Comments Theme 2: SAH Experience descriptions: Many participants took the opportunity to provide firsthand perspectives on their experiences after a SAH. Comments included 'I truly believe that I have recovered extremely well with virtually no physical deficits (apart from ongoing fatigue + + +)' and 'I went on to complete my Master and do a PhD after my recovery' as well as 'Having an aneurysm is a life changing experience'. Some participants emphasized challenges such as 'new problems are developing; especially balance and vestibular issues like vertigo' and '[My SAH] makes it difficult for me to read; understand and retain information' as well as 'Based on my experiences; the trauma and mental health piece was never addressed'.

Discussion

In this international, online Delphi survey, stakeholders (including an important proportion (59%) of participants with lived experience) identified 32 domains considered to be of critical importance to measure following aSAH. The highest ranked domains were Life Impact domains including cognitive and executive function, the ability to walk, and basic activities of daily living. Pathophysiological outcomes including aneurysm obliteration, cerebral infarction, delayed

Table 1 Results from the ranking round (Round 4) of domains achieving consensus and the rankings according to the average Likert scale score after Round 2 when all 73 domains were assessed by participants. The results from the ranking round are also presented by stakeholder group

Domain	Overall ranking	Ranking by mean Likert score after Round 2	SAH patient or caregiver ranking	Clinician or health care professional ranking	Researcher or industry professional ranking
Cognition and Executive Function	1	7	1	2	1
Aneurysm obliteration	2	4	2	3	14
Cerebral infarction	3	11	10	4	7
Functional outcomes including ability to walk	4	6	9	5	2
Delayed cerebral ischemia	5	12	24	1	5
The overall quality of life as reported by the SAH survivor	6	9	13	7	3
Changes to emotions or mood (including depression)	7	16	3	18	8
The basic activities of daily living (BADLs); ability to provide basic self care	8	8	12	8	4
Vasospasm	9	23	8	10	19
ICU Complications	10	30	19	6	18
Rebleeding	11	5	11	14	15
Instrumental activities of daily living (IADLs) which enable people to live independently	12	10	17	13	6
Verbal communication	13	13	6	21	10
Death – overall	14	1	18	11	9
The ability to maintain concentration or focus	15	15	5	23	16
Memory changes	16	24	4	28	17
Return to previous role/returning to baseline	17	27	23	9	13
Decision-making ability (e.g. speed)	18	31	7	24	12
Early brain injury	19	26	20	12	29
Availability and access to any type of therapy	20	14	15	17	20
Physical health of person with aneurysm	21	26	16	22	26
Understanding what is happening/what will happen; information and education for patients and their families	22	17	14	27	28
Survival to a specific time point such as three months after the initial SAH	23	2	25	15	21
Recanalization; Recurrence; or Retreatment	24	18	21	19	30
Caregiver and family support for person with aneurysm; including emotional support	25	20	22	30	23
A measure of the overall quality of care	26	19	31	16	25
Alteration of consciousness	27	21	32	20	11
Impact on the physical and mental health of family and caregivers	28	29	27	25	22
Overall financial impact on the patient or family	29	28	26	31	24
Destination after discharge from hospital	30	22	29	26	27
Taking care of children	31	32	30	29	31
Survival to hospital discharge	32	3	28	32	32

🟧	Pathophysiological domains
🟦	Life impact domains
🟩	Survival domains
🟥	Resource use domains

cerebral ischemia, and vasospasm were also highly ranked. The quality of life as reported by the survivor and changes to mood and emotions rounded out the top ten.

Our results are consistent with those of an international q-sort survey of aSAH stakeholders from 25 different countries which found similar domains prioritized [29]. Results from both surveys show a mismatch in the existing aSAH RCT literature between the outcomes selected by researchers and those prioritized by key stakeholders including patients and their families. Patient-reported quality of life and assessments of mood and depression were among the highest rated domains by participants in this study, yet they are rarely reported in the literature, with only 8.5% of aSAH randomized trials reporting a QoL measure and less than 2% reporting assessments of mood or depression [7]. The comment from one participant about what is going on that cannot be seen is especially pertinent in this context. This demonstrates the importance of asking stakeholders' priorities directly rather than relying on past publications when selecting outcome measures.

The addition of a fourth round to enable ranking was relatively novel when compared to other Delphi surveys that have been used to prioritize outcomes in COS development [23–25]. We noted some distinct differences between the ranking of some domains depending on whether the Likert scoring method was used or an overall ranking process. This was most striking with respect to the survival domains which were scored highly for importance on Likert scales but ranked low when participants were asked to identify a top ten. This finding may have important implications for other COS developers who do not have the additional ranking round used in this survey and is worthy of further investigation in other contexts.

Our study has strengths. Firstly, we placed those with lived experience of aSAH at the centre of this work. We have had patient research partners involved in every step of the research process and almost 60% of the survey participants have direct lived experience as either survivors of aSAH or as a family member. We had high completion rates and maintained a high level of engagement across the four rounds of the survey. Additionally, we have used systematic and rigorous methodology. Delphi surveys are a well-accepted method; the iterative process encourages the development of consensus while allowing equal voice to all participants.

There are limitations to our work. Many domains were considered critically important (32/73), more than can be included in an eventual COS. This was mitigated by the a priori planned additional ranking round to help inform subsequent stages of the COS development. There is a risk of survivor bias in participants from the lived experience group, and this was commented on by one participant with the statement 'if you die all else are unimportant'. We have included caregivers in the lived experience group to reduce this risk, but survivor bias should be considered in subsequent stages of the COS development.

The results of our survey are critical in the development of an aSAH COS and help inform clinicians, researchers, and policy makers what aspects of health are most important when designing and evaluating new interventions in aSAH. The next step in the COS development process is a consensus meeting to finalize a core domain set as per standard OMERACT methods. Further stakeholder engagement will address the uncertainty on the optimal time points to measure the consensus domains. Finally, we will evaluate the feasibility, truth, and discrimination of specific measurement instruments to characterize the chosen core domains and finalize the aSAH COS [15].

Conclusion

In this international Delphi survey, we have identified a range of domains considered to be of critical importance to a mixed group of stakeholders, of which the majority have direct lived experience with aSAH. Our results confirm that there is a mismatch between the outcomes reported in aSAH research and those prioritized by patients, family members, caregivers, health care providers, and researchers. Developing a COS in aSAH will help address this mismatch, improve research efficiency, and aid knowledge translation. The results of our study are a key step in the process for developing an aSAH-specific COS.

Appendix 1. Delphi invitation email text

Registration Email

Subject Line: Confidential: Invitation to participate in research.

Hello,

You are being asked to participate in a research study that we are conducting.

Participation is voluntary. You can choose to end your participation in this research (called withdrawal) at any time without having to provide a reason.

Introduction: You are being asked to participate because you or your loved one has experienced a brain aneurysm called a "subarachnoid hemorrhage" (SAH) / you are a health care professionals with self-identified experience managing and/or caring for people with SAH / you are a research, industry professional, or funder with self-identified experience, expertise, and/or focus in SAH.

Our goal is to create a list of outcomes that patients/families, clinicians, and researchers value, agree on, and think should be included in all future research in SAH, called a Core

Outcome Set (or “COS”). This survey will be used to identify which outcomes are most important to each group and when these outcomes should be measured during recovery.

What you will do: Your participation in this study will require the completion of a 3-part survey. The survey asks you to rate the importance of each SAH outcome and timepoint during SAH recovery. Each round should take approximately 1 h of your time.

How to register: You will be asked to register for participation in the survey by providing your email address and by creating a username and password. This email address will be used to send you reminders to complete the different steps of the survey and to link your survey answers to you throughout the survey rounds.

You may feel that you fall into more than one group, but we ask that you please choose to register in the group that best describes your **primary role** with respect to subarachnoid hemorrhage:

1) *SAH patient or family member/caregiver* group—you or your loved one has experienced a brain aneurysm called a “subarachnoid hemorrhage”, or
2) *Clinician or health care professional* group—you are a health care professional with self-identified experience managing and/or caring for people with SAH, or
3) *Researcher, industry professional, or funder* group—you are a researcher (published peer reviewed article or similar in SAH research in the past 5 years), an industry professional (including pharmaceutical), or a funder with self-identified experience, expertise, and/or focus in SAH.

Privacy and confidentiality: Your email address will not be used for any other purposes and will not be visible to the study team or any other participants. Therefore, the survey is anonymous, which means that your answers will not be traced back to you. If the results of this study are published, your identity will remain confidential.

However, please note that your email, username, and password will be stored on the University of Liverpool’s secure servers in England. The University of Liverpool is the creator of the survey software DelphiManager®. DelphiManager® uses your email address to send you reminders and to link your survey answers to you throughout the survey rounds. This data will be deleted from University of Liverpool servers 6 months after the survey has ended.

If you would like to participate in this study please click on the link below to access the Survey/Questionnaire: **[link].**

By completing the survey/questionnaire, you are providing your consent to participate in the study.

If you have any questions, please contact the Research Coordinator at [email address redacted].

Thank you,
SAH Core Outcome Set Working Group.
Ottawa Hospital Research Institute (OHRI).

Appendix 2. Domains and definitions presented to Delphi participants

Domain	Definition for this domain (will appear as Help Text to help respondents understand the domain)	OMERACT core area
Aneurysm obliteration	Whether the treatment for aneurysm (e.g. clipping, coiling) was successful	Pathophysiological manifestations
Anxiety and/or PTSD	Feelings of anxiety and/or symptoms of post-traumatic stress disorder (PTSD)	Pathophysiological manifestations
Verbal communication	Verbal communication, including difficulty with speech and word finding (i.e. words are on the “tip of the tongue”). For example, experiencing aphasia or difficulty communicating	Pathophysiological manifestations
Pain related to SAH, such as headache and backpain	The frequency and severity of pain related to the SAH such as headache or backpain	Pathophysiological manifestations
Balance/vestibular issues	Changes in balance and/or increased dizziness or vertigo	Pathophysiological manifestations
Cerebral infarction	Damage to brain tissues due to stroke	Pathophysiological manifestations
Cognition and executive function	Changes to thinking, memory, learning, and perception, and the control or coordination of these abilities to pay attention, organize, plan, regulate emotions, create goals, completing tasks, etc	Pathophysiological manifestations
The ability to maintain concentration or focus	Changes in ability to concentrate or focus on tasks	Pathophysiological manifestations

Domain	Definition for this domain (will appear as Help Text to help respondents understand the domain)	OMERACT core area
Cerebral spinal fluid (CSF) flow and/or shunt dependency	Issues with CSF flow including hydrocephalus and the requirement for a flow diverting shunt	Pathophysiological manifestations
Delayed cerebral ischemia	A common complication in the days after SAH associated with worse outcomes	Pathophysiological manifestations
Decision-making ability (e.g. speed)	The speed for making decisions and the processing of information for making decisions	Pathophysiological manifestations
Changes to emotions or mood (including depression)	Feeling more emotional or less emotional (e.g. feeling numb, less reactive). Symptoms of depression and/or generally experiencing changes to mood (e.g. increased feelings of frustration)	Pathophysiological manifestations
Sensory overload	Environment tends to overwhelm or over-stimulate one or more senses. For example, distress from crowds or other noises	Pathophysiological manifestations
Early brain injury	Immediate injury to the brain after SAH identified using CT, MRI, serum/CSF biomarker, etc	Pathophysiological manifestations
Ensuring other potential health issues aren't missed	Making sure that health conditions that are not related to the aneurysm are not overlooked	Pathophysiological manifestations
ICU complications	Any infections, pain, or other illnesses related to spending time in the ICU	Pathophysiological manifestations
Vasospasm	Narrowing of the arteries in the days and weeks after SAH	Pathophysiological manifestations
Lack of taste and/or smell	Changes in or reduced taste and/or smell	Pathophysiological manifestations
Memory changes	Problems with memory or changes to memory	Pathophysiological manifestations
Functional outcomes including ability to walk	Patient's physical ability or Neurofunctional disability, i.e. any changes in physical health of person with aneurysm. This includes ability to walk with or without a cane	Pathophysiological manifestations
Pituitary function	Hormonal changes	Pathophysiological manifestations
Physical health of person with aneurysm	Decline or changes in physical health of the person with the aneurysm	Pathophysiological manifestations
Rebleeding	Subsequent bleeding after treatment of the aneurysm	Pathophysiological manifestations
Recanalization, recurrence, or retreatment	Restoring blood flow to blood vessels after obstruction, having to receive more treatment for aneurysm after initial treatment for SAH	Pathophysiological manifestations
Seizure	Experiencing one or more seizures	Pathophysiological manifestations
Sexual function/activity	Changes to sexual function or activity	Pathophysiological manifestations
Sleep, fatigue, or energy	Problems falling asleep, staying asleep, quality of sleep. Feelings of fatigue, overall tiredness, less energy that is not improved by amount of sleep	Pathophysiological manifestations
Speed of recovery	On overall measure of the time taken to recovery after SAH	Pathophysiological manifestations
Substance use/misuse/abuse	Increased use, misuse, or abuse of substances such as alcohol or drugs	Pathophysiological manifestations
Tracheotomy requirement	Need for a tracheotomy to help with breathing	Pathophysiological manifestations

Domain	Definition for this domain (will appear as Help Text to help respondents understand the domain)	OMERACT core area
Visual function	Changes to vision	Pathophysiological manifestations
Ability to attend social functions	Ability to attend social functions such as activities, church, etc	Life impact
Ability to multi-task	Ability to focus on more than one task at a time	Life impact
Ability to respond to emergencies	Ability to respond to an emergency in a way that promotes safety of the individual	Life impact
Ability to work/return to work/Struggling with work	Returning to work that was being done before SAH at any capacity (e.g. same workload, reduced workload) after SAH recovery	Life impact
Ability to write legibly/micrographia	Reduced ability to writing neatly or having small and cramped handwriting	Life impact
The basic activities of daily living (BADLs), ability to provide basic self-care	Ability to complete basic self-care tasks such as using the bathroom, bathing, dressing, and eating	Life impact
Caregiver and family support for person with aneurysm, including emotional support	Caregiver and family understanding of how to support the person with SAH, including providing emotional support	Life impact
Impact on the physical and mental health of family and caregivers	Changes to physical health and/or mental health of family and caregivers (e.g. PTSD, burnout, depression)	Life impact
The ability to drive after a SAH	Ability to drive	Life impact
Instrumental activities of daily living (IADLs) which enable people to live independently	Ability to complete tasks which enable you to live independently such as shopping, managing finances and medications, preparing meals and household chores	Life impact
Isolation and peer support/connection with other SAH survivors	Importance of peer support and groups that connect SAH survivors and families to other SAH survivors and families	Life impact
The overall quality of life as reported by the SAH survivor	Changes in overall well-being and enjoyment of life	Life impact
Return to previous role/returning to baseline	Returning to previous role in the household	Life impact
Social stigma of having had brain surgery	Feeling disapproval or discrimination from others after having brain surgery	Life impact
Spelling	Trouble spelling words	Life impact
Taking care of children	Ability to provide care for children	Life impact
Understanding what is happening/what will happen, information and education for patients and their families	Ability to understand the current situation or possible outcomes that could occur in the future	Life impact
Availability and access to any type of therapy	Availability and ability to access therapy such as occupational therapy, technology therapy, speech therapy, etc	Resource use
Destination after discharge from hospital	Destination after discharge from hospital, for example rehabilitation facility, home, long-term care facility, nursing home, etc	Resource use
Overall financial impact on the patient or family	Financial impact on SAH patient or family during hospital stay, recovery, rehabilitation, and ongoing care	Resource use

Domain	Definition for this domain (will appear as Help Text to help respondents understand the domain)	OMERACT core area
Hospital free days	Days spent outside of hospital during a period of time such as the first 6 months since the initial SAH	Resource use
Hospital staff performance with respect to patient experience	Impact of hospital staff on patients (e.g. knowledge and resources provided)	Resource use
Length of stay in hospital or ICU	Number of days spent in hospital and/or intensive care unit (ICU)	Resource use
Length of stay for rehabilitation	Number of days spent in rehabilitation	Resource use
A measure of the overall quality of care	The quality of care received in hospital or using other services	Resource use
Rehabilitation resource use	Importance of using rehabilitation resources	Resource use
Therapeutic intensity	Intensity of therapy during recovery (e.g. how many sessions, how long?)	Resource use
Use of medications	Importance of access to medications during recovery	Resource use
Death – overall	Number of deaths that occur overall (i.e. deaths in hospital plus deaths after discharge)	Death
Survival to hospital discharge	Being alive at the point of hospital discharge	Death
Survival to a specific time point such as three months after the initial SAH	Being alive at a certain timepoint after the initial SAH	Death

Appendix 3. Breakdown of health care professional by specialism

Row labels	Clinician or health care professional
Anaesthetist/anaesthetist	5
Intensive Care Specialist	33
Neurologist or stroke physician	5
Neurosurgeon	6
Non health care provider	
Nurse	2
Other	3
Physical therapist or physiotherapist	1
Psychologist	1
Radiologist	1
Speech therapist	
(blank)	1
Grand total	58

Appendix 4. Round 1 raw data (all stakeholders)

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Death – overall	154	8.23376623	2	1.2987013	15	9.74025974	137	88.961039
Survival to a specific time point such as three months after the initial SAH	154	8.22727273	1	0.64935065	14	9.09090909	139	90.2597403
Aneurysm obliteration	162	8.01851852	4	2.4691358	20	12.345679	138	85.1851852
Rebleeding	162	8.01851852	3	1.85185185	15	9.25925926	144	88.8888889
Survival to hospital discharge	154	8.00649351	1	0.64935065	21	13.6363636	132	85.7142857
Cognition and executive function	162	7.88888889	1	0.61728395	16	9.87654321	145	89.5061728
Cerebral infarction	162	7.82098765	3	1.85185185	24	14.8148148	135	83.3333333
Functional outcomes including ability to walk	162	7.81481481	2	1.2345679	23	14.1975309	137	84.5679012
Delayed cerebral ischemia	162	7.78395062	6	3.7037037	24	14.8148148	132	81.4814815
The basic activities of daily living (BADLs); ability to provide basic self-care	156	7.65384615	5	3.20512821	27	17.3076923	124	79.4871795
Vasospasm	162	7.58641975	7	4.32098765	30	18.5185185	125	77.1604938
The overall quality of life as reported by the SAH survivor	156	7.57051282	3	1.92307692	30	19.2307692	123	78.8461538

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Recanulization; recurrence; or retreatment	162	7.49382716	6	3.7037037	34	20.9876543	122	75.308642
The ability to maintain concentration or focus	162	7.41358025	1	0.61728395	36	22.2222222	125	77.1604938
Understanding what is happening/what will happen; information and education for patients and their families	156	7.37820513	2	1.28205128	36	23.0769231	118	75.6410256
Instrumental activities of daily living (IADLs) which enable people to live independently	156	7.37179487	4	2.56410256	37	23.7179487	115	73.7179487
Verbal communication	162	7.37037037	3	1.85185185	37	22.8395062	122	75.308642
Cerebral spinal fluid (CSF) flow and/or shunt dependency	162	7.36419753	10	6.17283951	38	23.4567901	114	70.3703704
Seizure	162	7.30246914	7	4.32098765	38	23.4567901	117	72.2222222
Ability to work/return to work/struggling with work	156	7.26282051	2	1.28205128	46	29.4871795	108	69.2307692

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Caregiver and family support for person with aneurysm; including emotional support	156	7.25641026	5	3.20512821	39	25	112	71.7948718
Availability and access to any type of therapy	154	7.24675325	2	1.2987013	41	26.6233766	111	72.0779221
ICU complications	162	7.19753086	8	4.9382716	40	24.691358	114	70.3703704
Early brain injury	162	7.17901235	9	5.55555556	37	22.8395062	116	71.6049383
Taking care of children	156	7.17307692	5	3.20512821	41	26.2820513	110	70.5128205
A measure of the overall quality of care	154	7.16233766	3	1.94805195	43	27.9220779	108	70.1298701
Changes to emotions or mood (including depression)	162	7.14814815	4	2.4691358	47	29.0123457	111	68.5185185
Memory changes	162	7.12962963	2	1.2345679	51	31.4814815	109	67.2839506
Physical health of person with aneurysm	162	7.08024691	0	0	58	35.8024691	104	64.1975309
Return to previous role/returning to baseline	156	6.99358974	5	3.20512821	45	28.8461538	106	67.9487179
Impact on the physical and mental health of family and caregivers	156	6.97435897	6	3.84615385	47	30.1282051	103	66.025641
Destination after discharge from hospital	154	6.97402597	4	2.5974026	56	36.3636364	94	61.038961
Visual function	162	6.96296296	6	3.7037037	56	34.5679012	100	61.7283951

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Decision-making ability (e.g. speed)	162	6.95061728	4	2.4691358	54	33.3333333	104	64.1975309
Rehabilitation resource use	154	6.92857143	3	1.94805195	57	37.012987	94	61.038961
Sleep; fatigue; or energy	162	6.91975309	6	3.7037037	56	34.5679012	100	61.7283951
Pain related to SAH; such as headache and backpain	162	6.90123457	5	3.08641975	56	34.5679012	101	62.345679
Overall financial impact on the patient or family	154	6.87662338	4	2.5974026	55	35.7142857	95	61.6883117
Tracheotomy requirement	162	6.83950617	15	9.25925926	53	32.7160494	94	58.0246914
Anxiety and/or PTSD	162	6.82098765	8	4.9382716	60	37.037037	94	58.0246914
Balance/vestibular issues	162	6.75308642	2	1.2345679	64	39.5061728	96	59.2592593
Use of medications	154	6.71428571	6	3.8961039	58	37.6623377	90	58.4415584
Therapeutic intensity	154	6.69480519	8	5.19480519	63	40.9090909	83	53.8961039
Ability to respond to emergencies	156	6.69230769	5	3.20512821	63	40.3846154	88	56.4102564
Pituitary function	162	6.67901235	17	10.4938272	59	36.4197531	86	53.0864198
Ensuring other potential health issues aren’t missed	162	6.64814815	9	5.55555556	61	37.654321	92	56.7901235
Hospital staff performance with respect to patient experience	154	6.50649351	10	6.49350649	62	40.2597403	82	53.2467532

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Length of stay for rehabilitation	154	6.50649351	9	5.84415584	70	45.4545455	75	48.7012987
Sensory overload	162	6.38888889	9	5.55555556	70	43.2098765	83	51.2345679
Length of stay in hospital or ICU	154	6.38311688	10	6.49350649	67	43.5064935	77	50
The ability to drive after a SAH	156	6.33974359	11	7.05128205	77	49.3589744	68	43.5897436
Hospital free days	154	6.30519481	20	12.987013	67	43.5064935	67	43.5064935
Speed of recovery	162	6.29012346	9	5.55555556	83	51.2345679	70	43.2098765
Isolation and peer support/connection with other SAH survivors	156	6.25	12	7.69230769	75	48.0769231	69	44.2307692
Ability to multi-task	156	6.06410256	10	6.41025641	85	54.4871795	61	39.1025641
Ability to write legibly/micrographia	156	6.01923077	15	9.61538462	80	51.2820513	61	39.1025641
Ability to attend social functions	156	6.00641026	11	7.05128205	85	54.4871795	60	38.4615385
Sexual function/activity	162	5.95679012	15	9.25925926	89	54.9382716	58	35.8024691
Lack of taste and/or smell	162	5.67283951	30	18.5185185	84	51.8518519	48	29.6296296
Substance use/mis-use/abuse	162	5.60493827	24	14.8148148	89	54.9382716	49	30.2469136
Spelling	156	5.46153846	27	17.3076923	82	52.5641026	47	30.1282051
Social stigma of having had brain surgery	156	5.05128205	42	26.9230769	77	49.3589744	37	23.7179487

Appendix 5. Added domains suggested by participants in Round 1 of the Delphi

Added Outcome Domains after Round 1
Alteration of consciousness
Fear
Hearing impairment
Infertility
Lack of will; drive; or initiative for action; speech; thought (Abulia)–
Partnership
Readmission to ICU
Spasticity/contractures
Surgical decompression
Swallowing function
Temperature regulation

Appendix 6. Round 2 raw data (all stakeholders)

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Death – overall	127	8.4488189	2	1.57480315	7	5.51181102	118	92.9133858
Survival to a specific time point such as three months after the initial SAH	127	8.4015748	2	1.57480315	6	4.72440945	119	93.7007874
Aneurysm obliteration	128	8.1796875	2	1.5625	15	11.71875	111	86.71875
Survival to hospital discharge	127	8.16535433	2	1.57480315	12	9.4488189	113	88.976378
Rebleeding	128	8.1171875	5	3.90625	6	4.6875	117	91.40625
Functional outcomes including ability to walk	128	8.09375	2	1.5625	11	8.59375	115	89.84375
Cognition and executive function	128	8.046875	1	0.78125	12	9.375	115	89.84375

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
The basic activities of daily living (BADLs); ability to provide basic self-care	127	7.94488189	3	2.36220472	18	14.1732283	106	83.4645669
Cerebral infarction	128	7.8125	3	2.34375	18	14.0625	107	83.59375
The overall quality of life as reported by the SAH survivor	127	7.79527559	3	2.36220472	24	18.8976378	100	78.7401575
Instrumental activities of daily living (IADLs) which enable people to live independently	127	7.76377953	4	3.1496063	15	11.8110236	108	85.0393701
Delayed cerebral ischemia	128	7.7578125	7	5.46875	17	13.28125	104	81.25
Verbal communication	128	7.4921875	2	1.5625	20	15.625	106	82.8125
Availability and access to any type of therapy	127	7.46456693	3	2.36220472	24	18.8976378	100	78.7401575
The ability to maintain concentration or focus	128	7.4140625	1	0.78125	28	21.875	99	77.34375
Recanulization; recurrence; or retreatment	128	7.3828125	6	4.6875	25	19.53125	97	75.78125

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Understanding what is happening/what will happen; information and education for patients and their families	127	7.37795276	1	0.78740157	31	24.4094488	95	74.8031496
Changes to emotions or mood (including depression)	128	7.3671875	2	1.5625	33	25.78125	93	72.65625
Vasospasm	128	7.3671875	7	5.46875	23	17.96875	98	76.5625
Alteration of consciousness	128	7.328125	3	2.34375	29	22.65625	96	75
A measure of the overall quality of care	127	7.31496063	3	2.36220472	31	24.4094488	93	73.2283465
Ability to work/return to work/struggling with work	127	7.30708661	3	2.36220472	35	27.5590551	89	70.0787402
Caregiver and family support for person with aneurysm; including emotional support	127	7.30708661	3	2.36220472	31	24.4094488	93	73.2283465
Destination after discharge from hospital	127	7.2519685	3	2.36220472	34	26.7716535	90	70.8661417
Seizure	128	7.21875	5	3.90625	32	25	91	71.09375
Memory changes	128	7.2109375	2	1.5625	33	25.78125	93	72.65625
Early brain injury	128	7.203125	5	3.90625	31	24.21875	92	71.875
Physical health of person with aneurysm	128	7.0703125	3	2.34375	41	32.03125	84	65.625

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Return to previous role/ returning to baseline	127	7.03937008	5	3.93700787	27	21.2598425	95	74.8031496
Taking care of children	127	7.03149606	7	5.51181102	28	22.0472441	92	72.4409449
ICU complications	128	7.015625	7	5.46875	30	23.4375	91	71.09375
Sleep; fatigue; or energy	128	7.0078125	2	1.5625	48	37.5	78	60.9375
Impact on the physical and mental health of family and caregivers	127	6.97637795	6	4.72440945	34	26.7716535	87	68.503937
Overall financial impact on the patient or family	127	6.97637795	4	3.1496063	41	32.2834646	82	64.5669291
Lack of will; drive; or initiative for action; speech; thought (Abulia)–	127	6.96850394	3	2.36220472	45	35.4330709	79	62.2047244
Cerebral spinal fluid (CSF) flow and/or shunt dependency	128	6.953125	11	8.59375	34	26.5625	83	64.84375
Anxiety and/or PTSD	128	6.859375	4	3.125	52	40.625	72	56.25
Decision-making ability (e.g. speed)	128	6.859375	4	3.125	46	35.9375	78	60.9375
Pain related to SAH; such as headache and backpain	128	6.8046875	4	3.125	50	39.0625	74	57.8125
Visual function	128	6.796875	7	5.46875	47	36.71875	74	57.8125

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Surgical decompression	127	6.78740157	10	7.87401575	49	38.5826772	68	53.5433071
Rehabilitation resource use	127	6.77165354	3	2.36220472	51	40.1574803	73	57.480315
Swallowing function	127	6.77165354	10	7.87401575	37	29.1338583	80	62.992126
Readmission to ICU	127	6.76377953	6	4.72440945	53	41.7322835	68	53.5433071
Use of medications	127	6.67716535	6	4.72440945	51	40.1574803	70	55.1181102
Ability to respond to emergencies	127	6.65354331	7	5.51181102	49	38.5826772	71	55.9055118
Balance/vestibular issues	128	6.640625	3	2.34375	55	42.96875	70	54.6875
Therapeutic intensity	127	6.59055118	6	4.72440945	56	44.0944882	65	51.1811024
Tracheotomy requirement	128	6.5859375	13	10.15625	44	34.375	71	55.46875
Ensuring other potential health issues aren't missed	128	6.5546875	7	5.46875	54	42.1875	67	52.34375
Hospital staff performance with respect to patient experience	127	6.45669291	6	4.72440945	64	50.3937008	57	44.8818898
Partnership	127	6.44094488	6	4.72440945	62	48.8188976	59	46.4566929
Length of stay in hospital or ICU	127	6.37007874	7	5.51181102	57	44.8818898	63	49.6062992
Spastiticity/contractures	128	6.3671875	13	10.15625	50	39.0625	65	50.78125
Fear	127	6.33858268	5	3.93700787	66	51.9685039	56	44.0944882
Sensory overload	128	6.3046875	10	7.8125	64	50	54	42.1875
Length of stay for rehabilitation	127	6.2992126	6	4.72440945	71	55.9055118	50	39.3700787

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Speed of recovery	128	6.296875	5	3.90625	77	60.15625	46	35.9375
Pituitary function	128	6.2578125	18	14.0625	51	39.84375	59	46.09375
Isolation and peer support/connection with other SAH survivors	127	6.22047244	8	6.2992126	72	56.6929134	47	37.007874
The ability to drive after a SAH	127	6.20472441	10	7.87401575	72	56.6929134	45	35.4330709
Hospital free days	127	6.13385827	15	11.8110236	68	53.5433071	44	34.6456693
Hearing impairment	128	6.0859375	18	14.0625	57	44.53125	53	41.40625
Ability to attend social functions	127	5.90551181	8	6.2992126	77	60.6299213	42	33.0708661
Sexual function/activity	128	5.890625	12	9.375	77	60.15625	39	30.46875
Ability to multi-task	127	5.88188976	8	6.2992126	85	66.9291339	34	26.7716535
Ability to write legibly/micrographia	127	5.7480315	12	9.4488189	82	64.5669291	33	25.984252
Temperature regulation	128	5.5703125	17	13.28125	76	59.375	35	27.34375
Substance use/mis-use/abuse	128	5.5078125	17	13.28125	79	61.71875	32	25
Lack of taste and/or smell	128	5.453125	27	21.09375	73	57.03125	28	21.875
Spelling	127	5.19685039	26	20.4724409	78	61.4173228	23	18.1102362
Infertility	128	4.9609375	38	29.6875	60	46.875	30	23.4375
Social stigma of having had brain surgery	127	4.83464567	38	29.9212598	68	53.5433071	21	16.5354331

Appendix 7. Round 3 raw data (all stakeholders) with consensus domains from Round 2 removed

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Caregiver and family support for person with aneurysm; including emotional support	124	7.475806	1	0.806452	20	16.12903	103	83.06452
Understanding what is happening/what will happen; information and education for patients and their families	124	7.451613	2	1.612903	25	20.16129	97	78.22581
Alteration of consciousness	125	7.416	5	4	13	10.4	107	85.6
Ability to work/ return to work/ struggling with work	124	7.362903	2	1.612903	29	23.3871	93	75
Return to previous role/returning to baseline	124	7.120968	5	4.032258	21	16.93548	98	79.03226
Overall financial impact on the patient or family	124	7.112903	4	3.225806	27	21.77419	93	75

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Physical health of person with aneurysm	125	7.08	4	3.2	27	21.6	94	75.2
Sleep; fatigue; or energy	125	7.008	1	0.8	48	38.4	76	60.8
Decision-making ability (e.g. speed)	125	7	2	1.6	37	29.6	86	68.8
Seizure	125	7	8	6.4	33	26.4	84	67.2
Visual function	125	6.96	7	5.6	40	32	78	62.4
Readmission to ICU	124	6.943548	7	5.645161	44	35.48387	73	58.87097
Lack of will; drive; or initiative for action; speech; thought (Abulia)–	124	6.935484	6	4.83871	33	26.6129	85	68.54839
Cerebral pinal fluid (CSF) flow and/or shunt dependency	125	6.88	12	9.6	37	29.6	76	60.8
Anxiety and/or PTSD	125	6.808	4	3.2	46	36.8	75	60
Swallowing function	124	6.758065	14	11.29032	24	19.35484	86	69.35484
Use of medications	124	6.717742	4	3.225806	43	34.67742	77	62.09677
Pain related to SAH; such as headache and backpain	125	6.712	4	3.2	47	37.6	74	59.2

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
Rehabilitation resource use	124	6.709677	1	0.806452	56	45.16129	67	54.03226
Ability to respond to emergencies	124	6.685484	5	4.032258	52	41.93548	67	54.03226
Surgical decompression	124	6.685484	6	4.83871	56	45.16129	62	50
Hospital staff performance with respect to patient experience	124	6.653226	3	2.419355	64	51.6129	57	45.96774
Tracheotomy requirement	125	6.64	14	11.2	40	32	71	56.8
Therapeutic intensity	124	6.604839	4	3.225806	60	48.3871	60	48.3871
Length of stay in hospital or ICU	124	6.532258	4	3.225806	58	46.77419	62	50
Balance/vestibular issues	125	6.472	7	5.6	57	45.6	61	48.8
Ensuring other potential health issues aren’t missed	125	6.464	7	5.6	54	43.2	64	51.2
Spastiticity/contractures	125	6.456	10	8	52	41.6	63	50.4
Sensory overload	125	6.36	5	4	76	60.8	44	35.2
Fear	124	6.354839	4	3.225806	74	59.67742	46	37.09677
Partnership	124	6.346774	5	4.032258	64	51.6129	55	44.35484
Length of stay for rehabilitation	124	6.322581	2	1.612903	80	64.51613	42	33.87097
Hearing impairment	125	6.288	12	9.6	65	52	48	38.4

Outcome measure	Responses	Average score	1–3	Low %	4–6	Mod %	7–10	High %
The ability to drive after a SAH	124	6.274194	7	5.645161	75	60.48387	42	33.87097
Speed of recovery	125	6.272	4	3.2	81	64.8	40	32
Hospital free days	124	6.233871	12	9.677419	64	51.6129	48	38.70968
Isolation and peer support/connection with other SAH survivors	124	6.177419	6	4.83871	75	60.48387	43	34.67742
Pituitary function	125	6.152	20	16	50	40	55	44
Ability to multitask	124	5.943548	7	5.645161	85	68.54839	32	25.80645
Ability to attend social functions	124	5.927419	7	5.645161	83	66.93548	34	27.41935
Ability to write legibly/micrographia	124	5.798387	10	8.064516	87	70.16129	27	21.77419
Sexual function/activity	125	5.688	11	8.8	88	70.4	26	20.8
Temperature regulation	125	5.56	18	14.4	81	64.8	26	20.8
Lack of taste and/or smell	125	5.52	22	17.6	79	63.2	24	19.2
Substance use/mis-use/abuse	125	5.512	17	13.6	84	67.2	24	19.2
Spelling	124	5.08871	27	21.77419	77	62.09677	20	16.12903
Infertility	125	4.928	36	28.8	64	51.2	25	20
Social stigma of having had brain surgery	124	4.693548	43	34.67742	60	48.3871	21	16.93548

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Canadian Critical Care Trials Group consortium:

The Canadian Critical Care Trials Group (CCCTG) is “a pan-Canadian partnership of multi-disciplinary, inter-professional researchers in acute and critical care, rehabilitation, long-term follow-up, public health, and out-patient care” (www.ccctg.ca).

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Availability of Data and Materials The datasets generated or analysed during the current study are not openly available as that was not a part of the Research Ethics Board approval for this study, but are available from the corresponding author upon reasonable request. This may require inter-institutional data-sharing agreements to be put in place. Data are located in controlled access data storage at the Ottawa Hospital Research Institute.

Declarations

Ethical Approval Ethical approval for the survey development work was provided by the Ottawa Health Science Network Research Ethics Board (Reference 20210028-01H). The participants consented to participate upon registration using the web-based Delphi Manager and we informed participants that they could withdraw at any time.

Conflict of Interest Shane English is a recipient of the Heart and Stroke Foundation of Canada National New Investigator Award. The authors have no relevant financial or non-financial interests to disclose. The authors have no conflicts of interest to declare that are relevant to the content of this article. All authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.
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