Determining “How” the Subarachnoid Hemorrhage Core Domains Should be Measured

Working Group Handbook

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1. Introduction

The purpose of this handbook is to provide you with information on what you can expect from your involvement in this project. You are not expected to read the entire handbook; however, you may find it to be a useful resource as we progress.

1.1. Welcome and learning videos

Thank you for your willingness to contribute to our development of a Core Outcome Set for aneurysmal Subarachnoid Hemorrhage (aSAH).

To welcome you to our international collaboration and help everyone start with the same background information, we have prepared a series of short videos. These videos introduce the team, the project, and how working group members will contribute. We ask all members to watch them before beginning the first activity.

Please watch the videos here:

1. Welcome and introduction
2. Introducing the team
3. The instrument selection process
4. More information: What are Core Outcome Sets (Content developed by the COMET Initiative)

1.2. Why are we doing this project?

This project began with a clear need: aSAH research needs greater consistency in what outcomes are measured and reported.

Outcomes are the specific aspects of injury, recovery, health, and well-being that researchers and clinicians measure. Measuring the right outcomes is crucial to understanding the true impact of injury, identifying effective treatments, and providing the most benefit to patients.

At present, however, there is little consistency in the outcomes measured and reported in aSAH research. Hundreds of different outcomes are used across studies.

This is problematic because:

1. It is hard to compare or combine findings across aSAH studies since they generally measure different things. This represents an inefficient use of limited resources and weakens our ability to determine which treatments, services, and supports are most effective.

2. Clinicians and researchers may not measure the right information at the right time, or they may use tests created for other health conditions that miss important details specific to aSAH.
3. Reported measures often have not included the perspectives of people with lived experience of aSAH. This may mean that new treatments do not consider what is most important to those directly affected by aSAH.

We want to make aSAH research and practice better by addressing these problems. To achieve this, we are creating a Core Outcome Set – an agreed list of outcomes ("what") and the instruments to measure them ("how") – for aSAH (Figure 1).

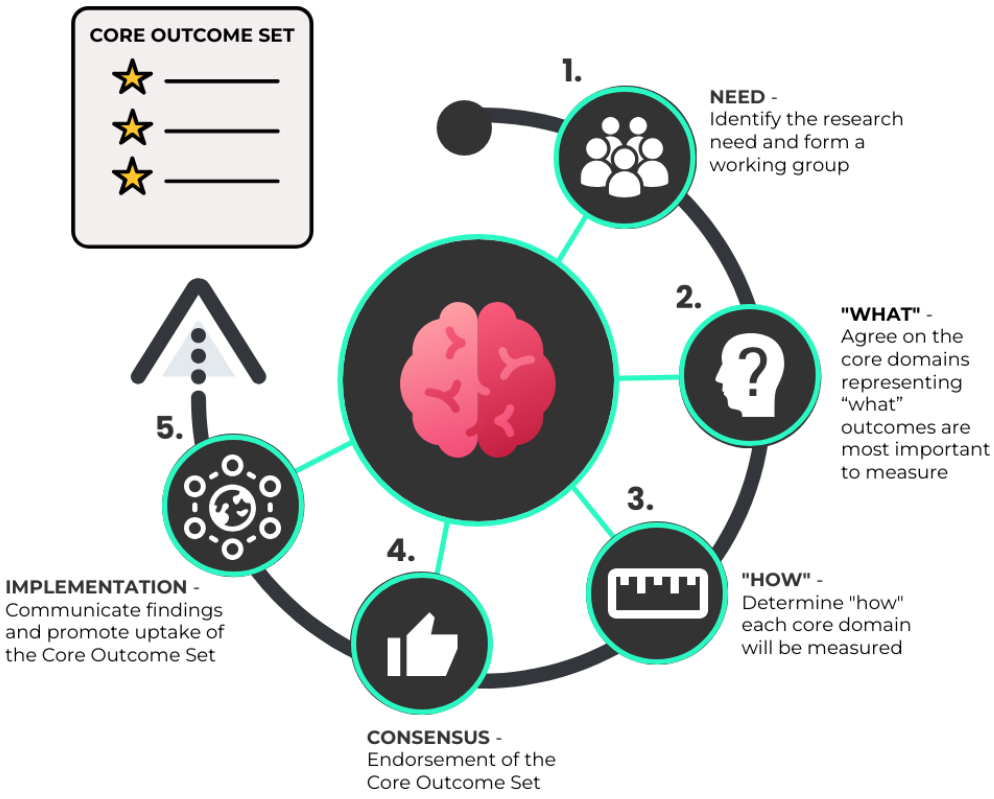


Figure 1. The Core Outcome Set development process

1.3. What have we done so far?

In the first major phase of this project, we identified and reached consensus on "What" outcomes matter most for aSAH. We called these outcomes the aSAH Core Domains. We identified 6 Core Domains (Figure 2).

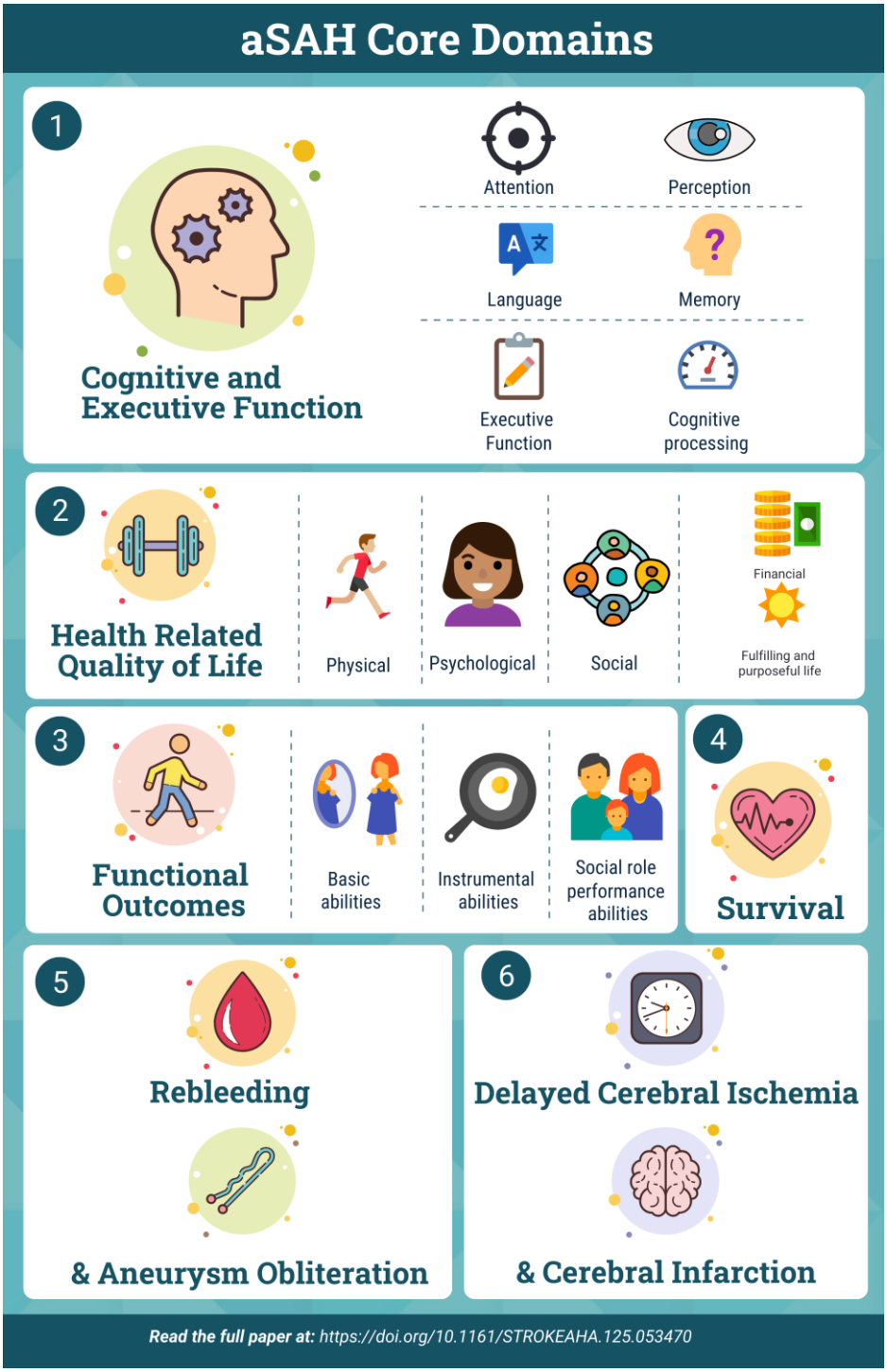


Figure 2. The aSAH Core Domains.

That phase answered the question: **"*What* should be measured?"**. You can read the full article here.

1.4. What are we doing now?

We are now beginning the next phase of our project, which asks: "***How* should each core domain be measured?**"

Together, we will use a transparent and systematic process to identify, assess, and recommend the best measurement instrument(s) for each core domain.

> **Measurement instrument:** Any tool, scale, or questionnaire used to measure an outcome.

1.5. Your role as a working group member

As a working group member, you will help us assess candidate measurement instruments for one or more of the core domains.

What we will ask you to do

We will ask you to draw on your clinical, research, and/or lived experience to help us decide whether instruments match the target domain, are practical to use, and have the appropriate measurement properties to be recommended for use in aSAH research and practice.

Time commitment

We will strive to make our requests targeted, manageable, and flexible. Most requests will involve reviewing a prepared evidence summary (prepared for you by our team) and completing a brief activity, such as a short survey. Wherever possible, we will aim for each activity to take about 5-15 minutes of your time. Requests will be completed virtually and asynchronously, to be adaptable to your schedule.

We will narrow the field of candidate instruments across multiple stages. The anticipated timeline for this entire process is approximately six months.

How your input will be used

Your input throughout this process will contribute to shaping which measurement instruments are used in future aSAH research.

The study team will summarize your group's feedback after each activity. The steering committee will review this feedback and use it to help guide decisions about which instruments should move forward for further consideration.

What you DO NOT need to do

You DO NOT need to search the literature, be an expert in every instrument/domain, or review/evaluate all evidence independently. The study team will conduct much of the time-intensive background work and prepare materials to support each activity (see section 2).

Your perspective matters

The success of this project depends on bringing together the right mix of individuals. We were very intentional with inviting you to join this collaboration because of the unique perspective and expertise that you bring – whether through your research, clinical, lived experience, or a combination of these – that is crucial for informing the Core Outcome Set.

We have kept the working groups relatively small and focused on a single domain so that all members will have an opportunity to be heard and see their input reflected in the final Core Outcome Set.

2. Instrument selection process

Our process for selecting instruments will be informed by the approach developed by the Outcome Measurement in Rheumatology (OMERACT) group.

This is a structured, multistep process. We will follow this process for every instrument being considered in each domain.

First, we will identify candidate instruments for each domain. Then those instruments will move through an instrument selection filter (Figure 3).

The filter asks four key questions:

1. Is the instrument a good match for the domain?
2. Is it feasible to use?
3. Do the numeric scores make sense?
4. Can it distinguish between groups of interest or detect change?

Once we have answered these questions, the working groups will recommend which instrument(s) should be used for measuring their domain.

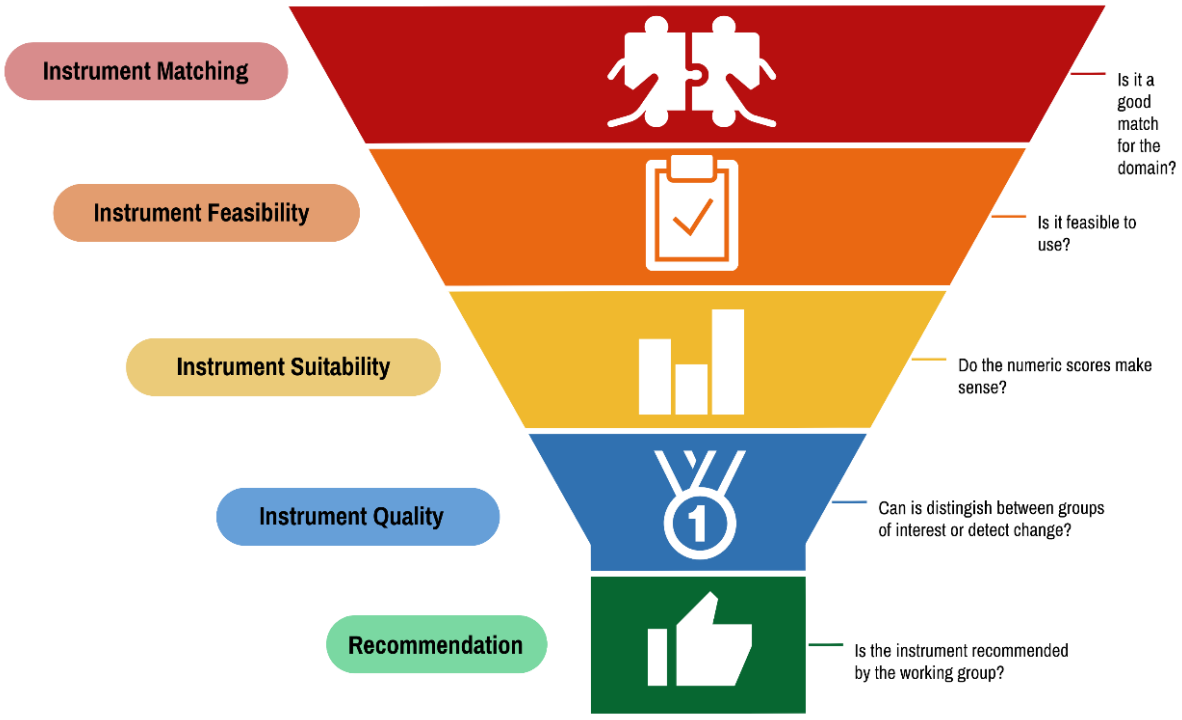


Figure 3. Instrument Selection Filter.

2.1. Step 1: Understand what you are trying to measure

The first step in our process is to make sure that everyone has a clear and shared understanding of the domain that their group is trying to measure.

What we will ask you to do
Review the definition for your Core Domain (Appendix 1) and the process that produced it. This definition will act as the main reference point against which candidate instruments will be compared to confirm that they truly measure the intended domain.

2.2. Step 2: Identify candidate instruments

Next, we need to identify the candidate instruments that could potentially measure each domain.

The study team has already completed much of this background work by reviewing the literature and identifying instruments used in previous research.

What we will ask you to do
Review the list of candidate instruments for your Core Domain and suggest adding any important instruments that may be missing and/or removing any irrelevant instruments.

2.3. Step 3: Domain match assessment

The first key question will be:

Is the instrument a good match for the domain as we have defined it?

This question will assess two related concepts.

The first is **face validity**: does the instrument appear to measure what it should?

The second is **content validity:** does the instrument capture all the important aspects of the domain?

This step ensures that any instruments we move forward actually measure the outcomes that we care about.

What we will ask you to do
Review brief descriptions of each instrument and answer whether the instrument appears to measure the intended domain.

2.4. Step 4: Feasibility assessment

The second key question will be:

Is the instrument feasible to use?

Feasibility includes practical considerations such as cost, time, accessibility, language availability, and ease of administration.

Working groups will consider feasibility from two perspectives.

First, working groups will consider the burden on the respondent or patient. For example, they will consider how much time, effort, or discomfort is involved in administering the instrument and whether it is understandable or acceptable for patients.

Second, working groups will consider the burden on the person, team, or system administering the instrument. For example, they will consider whether there are costs, licensing requirements, training needs, or equipment that could make the instrument impractical to use.

This step ensures that recommended instruments are realistic to use in research and practice.

What we will ask you to do
Review a summary of practical considerations for each instrument and answer questions about whether the instrument would be realistic and acceptable to use in aSAH research and practice.

2.5. Step 5: Narrow the field

After the domain match and feasibility assessments, our steering committee will review the results from the working groups.

The steering committee will then decide whether each instrument should move forward for full evaluation or be set aside because of concerns raised about its domain match or feasibility.

This step will narrow the field to the most relevant instruments that are worth the time and resources needed for full evaluation.

2.6. Step 6: Gather the evidence

For the instruments that move forward, the study team will find and summarize the available evidence on their measurement properties.

2.7. Step 7: Identify top instruments

Working groups will then review the evidence summaries prepared by the study team and answer the final two questions in the instrument selection filter.

Do the numeric scores make sense?

And

Can it distinguish between groups of interest or detect change?

What we will ask you to do
Review the measurement property summaries and assess the quality of evidence for each instrument. Then, answer questions on whether each instrument has acceptable measurement properties for measuring the target domain and has high-quality evidence supporting its use.

The steering committee will review the results and recommend the top instrument(s) from each group for formal ratification.

2.8. Step 8: Endorsement

The final step is endorsement.

Working groups will present a summary of their findings and recommendations to the wider international aSAH community.

After an opportunity for review and comment, we will hold a vote on whether the recommended instruments should be endorsed as part of our Core Outcome Set.

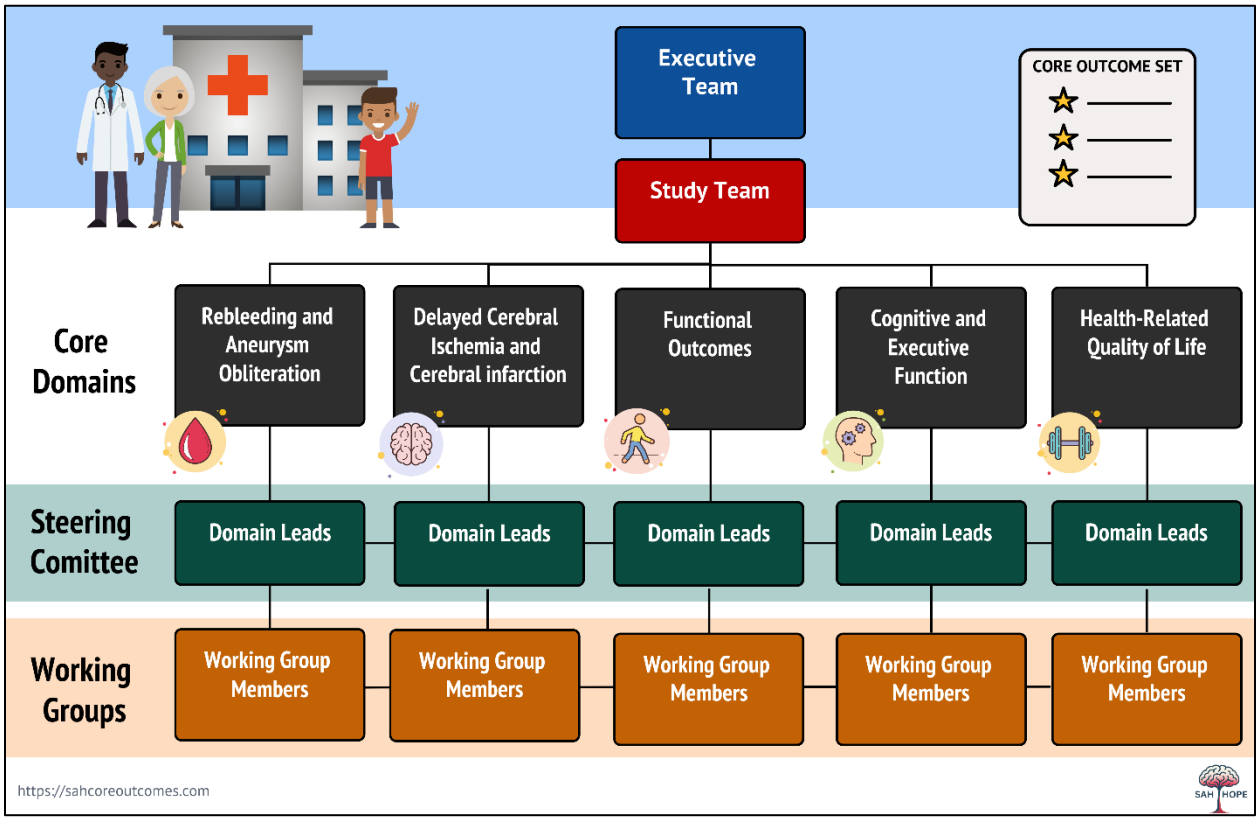
What we will ask you to do

Ideally, we would like representatives from each working group to present their group's work in person at the International Subarachnoid Hemorrhage Conference, to be held in Sydney, Australia, on November 17, 2026. Online participation will also be available. We encourage all working group members to be involved in the hybrid discussions surrounding this event and participate in the endorsement vote.

3. Organizational structure

We have organized this project into several connected teams. Each team will have distinct roles, enabling us to use members' time and expertise efficiently.

Although the teams have different roles, the process will be collaborative. Knowledge will move in all directions throughout this structure.



3.1 Executive team

The executive team provides overall leadership and direction for this project.

Executive team members:


Shane English


Chris Andersen


Justin Presseau


Beverley Shea


Maria Luisa

3.2. Study team

The study team will support the entire collaboration and will be your primary point of contact throughout the project.

The study team will coordinate the working groups and complete much of the time-intensive background work. This will include identifying candidate instruments, gathering evidence, preparing study materials, and synthesizing your feedback.

The study team will aim to make it as easy as possible for the working groups to focus their time on the questions where their expertise is most valuable.

Study team members:


Sean Patterson


Gordon Fernie


Yousif Al-Baldawi


Parinaz Paranjkhoo


Sara Cotter

3.3. Steering committee

The steering committee is made up of the leads for each core domain working group.

The steering committee will work closely with both the study team and their respective working groups. They will review the evidence and materials prepared by the study team and ensure the working groups' activities are focused, relevant, and manageable. They will also help interpret their working groups' feedback, resolve disagreements, and guide decisions about which instruments should move forward to the next assessment stage or be recommended for endorsement.

Rebleeding and Aneurysm Obliteration	Delayed Cerebral Ischemia and Cerebral Infarction	Functional Outcomes	Cognitive and Executive Function	Health Related Quality of Life
Redi Rahmani	Mervyn Vergouwen	Lachlan Donaldson	Ian Galea	Tracy Iona
Hemant Bhagat	Chiarra Robba	Isabel Hostettler	Christine Buckley	Sherry Chou
Katharina Busl		Leslie Miller	Phil Talbot	Jose Suarez

3.4. Working groups

The working groups bring together members with the relevant lived or professional experience for each core domain.

Working group members will evaluate candidate instruments drawing on their experience and supported by the evidence prepared by the study team.

4. General collaboration guidelines

To help keep the process focused, respectful, and manageable, we ask all members to follow these guidelines:

1. **Use the established sSAH Core Domains**

The aSAH Core Domains and their definitions were developed through an earlier consensus process. In this next phase, our focus is not to revise the domains or create new ones, but to identify the best instruments for measuring each of the established Core Domains.

2. **Review the background materials before each activity**

The study team will provide the background information needed for each activity. Please review this information before starting an activity and contact us if anything is unclear.

3. **Use plain language where possible**

Please avoid using acronyms and specialized terminology. If technical terms are needed, please define them.

4. **Draw on your experience only in ways that feel comfortable**

We welcome insights from clinical, research, and lived experience. However, you are not expected to share personal or distressing details. Please share only what feels appropriate and relevant to the activity.

5. **Respect different perspectives**

Members of this collaboration bring different types of expertise and may not always agree. We ask all members to engage respectfully and constructively.

5. Questions and support

If you have any questions about this project, the materials, or how to complete an activity, please contact one of the study team members below.

Sean Patterson
Email: sepatterson@ohri.ca

Gordon Fernie
Email: gfernie@ohri.ca

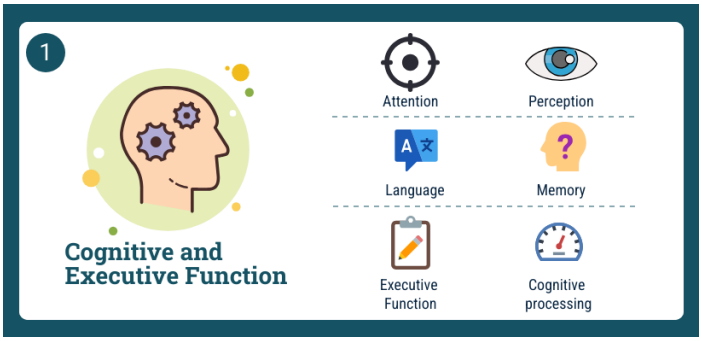
If you have any additional questions or concerns regarding this project, please contact one of the executive team members below.

Shane English
Email: senglish@toh.ca

Chris Andersen
Email: christopher.andersen@health.nsw.gov.au

Appendix 1. Core Domain definitions

Cognitive and Executive Function



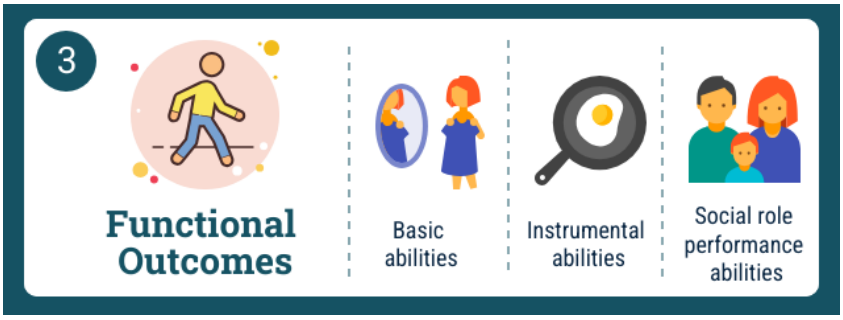
Cognitive and executive functions include the following interrelated processes:
Attention – The abilities to focus, shift, divide, or sustain attention on a particular stimulus or task or range of tasks.
Memory – the ability to recall in the short or long-term and the recognition of visual and verbal information, be it about experiences (episodic) or meaning (semantic).
Executive Function – involved in planning, abstract thinking, organization of thoughts, inhibition, conflict monitoring and multi-tasking.
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 the aptitude to visually search or scan for information, to draw or recreate visual images, and mentally manipulate objects two- and three-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 aSAH 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 include:

– 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 include:

– Completing activities essential to an individual's ability to function autonomously, including cooking, doing laundry, taking care of a home, managing money, shopping, getting to places beyond walking distance.

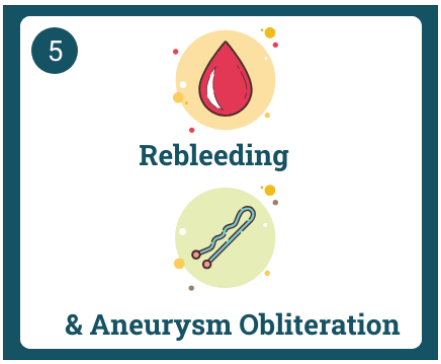
Social role performance abilities:

– Work, previous role in the household, social and family life at any capacity (e.g., same workload, reduced workload, etc.). The degree to which an individual can return to pre-hemorrhage baseline function on their journey of recovery.

Survival

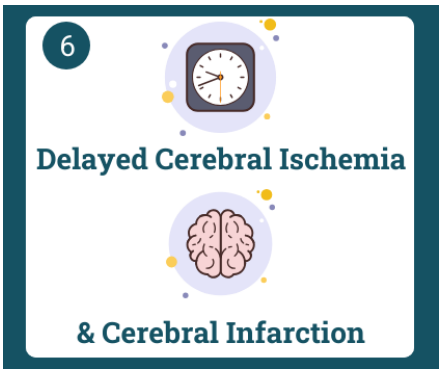
Survival is being alive at a given timepoint after an aSAH.

Rebleeding and Aneurysm Obliteration



Re-bleeding: A distinct second instance of bleeding from a cerebral aneurysm (before, during or after treatment of the aneurysm).
Aneurysm obliteration: Complete angiographic occlusion (e.g., clipping, coiling, etc.) resulting in elimination of a cerebral aneurysm from cerebral circulation.

Delayed Cerebral Ischemia and Cerebral Infarction



Delayed Cerebral Ischemia: 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 hour, 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.
Cerebral Infarction (CI): the presence of cerebral infarction on CT or MR scan of the brain within 6 weeks after an aSAH, or on the latest CT or MR scan made before death within 6 weeks, or proven at autopsy, not present on the CT or MR scan between 24 and 48 hours 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.