GLOSSARY OF TERMS

ACTIVITIES OF DAILY LIVING (ADLs): The basic tasks people do every day to look after themselves, such as eating, bathing, dressing, using the toilet, and getting in and out of bed or a chair. Questions about ADLs show how much help, if any, a person needs after a subarachnoid haemorrhage. In the aSAH Core Domains these are called "basic abilities" and are part of Functional Outcomes. See also Instrumental Activities of Daily Living (IADLs).

ANEURYSM NECK: The opening where the aneurysm joins the normal blood vessel it grew from (called the parent artery). A small pocket of aneurysm left at the neck after treatment is called a "neck remnant".

ANEURYSM OBLITERATION: How completely an aneurysm has been sealed off after treatment, so that blood can no longer flow into it. It is checked with pictures of the blood vessels (such as an angiogram, CTA or MRA), soon after treatment and again months later. Results are usually sorted into grades, for example: completely sealed, a small amount left at the neck, or part of the aneurysm still filling with blood. An aneurysm that is not fully sealed may grow back or bleed again. Rebleeding and Aneurysm Obliteration together make up one of the six aSAH Core Domains.

ANGIOGRAM (CATHETER ANGIOGRAPHY OR DSA): The test that gives the most detailed pictures of the blood vessels in the brain. A thin, flexible tube (catheter) is put into an artery in the groin or wrist and guided up to the neck. Dye (contrast) is injected and X-ray pictures are taken as it flows through the blood vessels. Doctors may call it "digital subtraction angiography" or "DSA". It is usually the reference ("gold standard") test for judging whether an aneurysm has been fully sealed.

AREA UNDER THE CURVE (AUC): A single number that sums up how well a test or score can tell apart people who have a condition (or outcome) from people who do not. It usually ranges from 0.5 to 1.0. An AUC of 0.5 means the test is no better than tossing a coin; 1.0 means it is perfect. As a rough guide, values above 0.7 are considered acceptable and above 0.8 good. It is sometimes called the "C-statistic".

BRAIN ANEURYSM: An aneurysm (AN-yer-iz-im) is a bulge in a blood vessel. It happens because there's a weak spot in the blood vessel wall. A brain aneurysm is in

one of the blood vessels that carry blood to the brain. It is the most common cause of a subarachnoid haemorrhage.

CANDIDATE INSTRUMENT: A measurement instrument that is being considered for the Core Outcome Set. Working groups review the candidate instruments for their domain and help decide which ones should move forward.

CEREBRAL INFARCTION (CI): An area of brain tissue that has been permanently damaged because it did not get enough blood and oxygen. This is what most people know as a stroke. After a subarachnoid haemorrhage it can be caused by delayed cerebral ischaemia (DCI) or, less often, by a complication of aneurysm treatment. It can be seen on a CT or MRI scan. Delayed Cerebral Ischaemia and Cerebral Infarction together make up one of the six aSAH Core Domains.

CLIPPING: See Neurosurgical (micro)clipping.

COGNITIVE AND EXECUTIVE FUNCTION: One of the six aSAH Core Domains. It covers thinking skills, including attention, memory, language, perception (making sense of what we see and hear), executive function (planning, organising, multi-tasking and controlling impulses) and the speed of thinking (cognitive processing).

COILING: See Endovascular aneurysm repair.

CONTENT VALIDITY: Whether a measurement instrument covers all the important parts of what it is meant to measure. For example, a memory test that only checks short-term memory, and not long-term memory, would have poor content validity.

CONTRAST (DYE): A liquid injected into a vein or artery that shows up brightly on scans and X-rays, so that blood vessels and blood flow can be seen clearly.

CORE DOMAIN SET: A Core Domain Set is the list of domains that experts agree must be used to measure an illness or health condition.

CORE OUTCOME SET (COS): A Core Outcome Set includes decisions on when and how to measure the Core Domains. It is the agreed minimum set of outcomes that should be measured and reported in all studies of a health condition, so that results can be compared and combined. For subarachnoid haemorrhage, the Core Domains (what to measure) have already been agreed. The current work focuses on choosing the measurement instruments (how to measure).

CT (COMPUTED TOMOGRAPHY): A type of X-ray scan that takes many pictures from different angles to create detailed “slices” of the brain. It is quick and widely

available, and is usually the first scan done to look for bleeding in or around the brain. Sometimes called a “CAT scan”.

CTA (CT ANGIOGRAPHY): A CT scan done while dye (contrast) is injected into a vein in the arm. It shows the blood vessels of the brain and is often used to find an aneurysm, or to check it after treatment. Metal clips and coils can cause streaks on the pictures that make them harder to read.

CTP (CT PERFUSION): A CT scan, done with dye (contrast), that shows how much blood is reaching different parts of the brain. It can help show areas that are not getting enough blood, for example during delayed cerebral ischaemia.

DELAYED CEREBRAL ISCH(A)EMIA (DCI): Ischaemia (iss-KEE-mee-ah) means that part of the body is not getting enough blood flow. DCI is a complication that usually happens between about 3 and 14 days after the subarachnoid haemorrhage, and happens for a number of different reasons, not yet completed understood. It can cause new symptoms such as confusion, drowsiness, weakness or trouble speaking. If it is not reversed, it can lead to a cerebral infarction (stroke). Narrowing of the brain arteries (vasospasm) is one important cause, but not the only one. Delayed Cerebral Ischaemia and Cerebral Infarction together make up one of the six aSAH Core Domains.

DOMAIN: A domain is any milestone, symptom, characteristic or attribute that can be measured.

EEG (ELECTROENCEPHALOGRAPHY): A painless test that records the brain’s electrical activity using small sensors placed on the scalp. It is used to look for seizures, including seizures that do not cause any shaking. In intensive care, continuous EEG may also pick up changes in brain activity that can be an early warning sign of delayed cerebral ischaemia.

ENDORSEMENT: The final step in choosing an instrument for the Core Outcome Set. Working groups present their recommendations, everyone has a chance to discuss them, and participants then vote on whether each recommended instrument should become part of the Core Outcome Set.

ENDOVASCULAR ANEURYSM REPAIR: Treating an aneurysm from inside the blood vessel, without opening the skull. As with an angiogram, a thin tube (catheter) is passed from an artery in the groin or wrist up to the aneurysm. The most common method is coiling: very soft, thin platinum wires are fed into the aneurysm, where they curl up and fill it so that the blood inside clots and the aneurysm is sealed off.

Other endovascular methods include stents (small mesh tubes that hold coils in place), flow-diverting stents and the WEB device (see below). Also called "endovascular treatment" or "endovascular coiling".

FACE VALIDITY: Whether a measurement instrument, at first glance, looks like it measures what it is supposed to measure.

FEASIBILITY: How practical an instrument is to use in real research and care. This includes cost, licence fees, time, training and equipment needed, the languages it is available in, and how much effort or discomfort it involves for the patient.

FLOW-DIVERTING STENT (FLOW DIVERTER): A fine, tightly woven mesh tube placed inside the parent artery, across the opening (neck) of the aneurysm. It redirects blood to flow along the normal artery instead of into the aneurysm. Blood inside the aneurysm slows down and clots, and over weeks to months the aneurysm seals off as the artery wall heals over the mesh. Because the aneurysm is not sealed straight away, and patients need blood-thinning medicines afterwards, flow diverters are used less often for aneurysms that have bled. This is also why special grading scales are used to judge how well they have worked.

FUNCTIONAL OUTCOMES: One of the six aSAH Core Domains. It describes how well a person can carry out everyday activities and take part in life. It includes basic abilities (activities of daily living), instrumental abilities (instrumental activities of daily living) and social role abilities, such as work, study, parenting and relationships.

GLASGOW OUTCOME SCALE – EXTENDED (GOSE): A commonly used scale that sorts a person's overall recovery after a brain injury into 8 levels, from 1 (death) to 8 (upper good recovery, meaning a return to normal life with no or only minor problems). It is usually completed through a structured interview with the person or a family member.

GRADING SCALE: A tool that sorts a person or a test result into ordered groups (grades), usually from best to worst. For example, aneurysm obliteration scales grade how completely an aneurysm has been sealed, from "completely sealed" to "part of the aneurysm still filling". Other grading scales used in subarachnoid haemorrhage include the WFNS and Hunt and Hess scales (how unwell a person is when they arrive in hospital) and the Fisher scale (how much blood is seen on the first CT scan).

HEALTH-RELATED QUALITY OF LIFE (HRQoL): One of the six aSAH Core Domains. It describes how a person's health affects their overall well-being, including physical, psychological (emotional) and social well-being, financial impact, and having a

fulfilling and purposeful life. It is usually measured with questionnaires completed by the person themselves.

INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLs): More complex everyday tasks that a person needs to be able to do to live independently, such as managing money, taking medicines correctly, shopping, cooking, housework, using the telephone, and getting around by car or public transport. In the aSAH Core Domains these are called "instrumental abilities" and are part of Functional Outcomes.

INTER-RATER RELIABILITY: How often two or more different people (raters) give the same score when they assess the same thing – for example, two doctors grading the same angiogram. High inter-rater reliability means the result does not depend much on who is doing the scoring. It is often reported as a "kappa" value, where 0 means no more agreement than chance and 1 means perfect agreement. A related term, intra-rater reliability, is how often the same person gives the same score when they assess the same thing twice.

MEASUREMENT INSTRUMENT: Any tool, scale, questionnaire, test or scoring system used to measure an outcome. Examples include a memory test, a quality of life questionnaire, or a scale for grading an angiogram.

MEASUREMENT PROPERTIES: The qualities that show how well a measurement instrument works. They include reliability (does it give consistent results?), validity (does it measure what it is supposed to?) and responsiveness (can it detect change?).

MODIFIED RANKIN SCALE (mRS): A commonly used scale, from 0 to 6, that rates a person's overall level of disability or dependence in daily life after a stroke or brain injury. 0 means no symptoms at all, 5 means severe disability needing constant care, and 6 means death.

MRA (MAGNETIC RESONANCE ANGIOGRAPHY): An MRI scan that shows the blood vessels. It can sometimes be done without dye and does not use X-rays, so it is often used for follow-up checks of coiled aneurysms over months and years.

MRI (MAGNETIC RESONANCE IMAGING): A scan that uses a strong magnet and radio waves (not X-rays) to take very detailed pictures of the brain. It is better than CT at showing small areas of brain damage, such as small strokes. It takes longer than a CT scan, is noisy, and means lying still inside a narrow tunnel. Some people with certain metal implants or devices cannot have an MRI.

NEUROSURGICAL (MICRO)CLIPPING: A brain operation to seal off an aneurysm. The neurosurgeon makes a small opening in the skull (a craniotomy) and, using an

operating microscope, places a tiny metal clip across the neck of the aneurysm. This stops blood from getting into the aneurysm. The clip stays in place permanently.

OMERACT: stands for Outcome Measures in Rheumatology. OMERACT is a global, volunteer-driven, not for profit organisation committed to improving outcomes for patients with autoimmune and musculoskeletal diseases through advancing the design and quality of clinical studies. Through rigorous methodology and our global Working Groups, OMERACT supports the development of Core Outcome Sets (COS), identifying patient and disease-relevant areas to be measured (domains) and the corresponding measurement instruments for use in clinical trials, including those for regulatory approval of new treatments. SAH HOPE is using the processes developed by OMERACT, first to agree on the Core Domain Set for subarachnoid haemorrhage from brain aneurysm, and now to choose the measurement instruments for each Core Domain.

OUTCOME: A result or change in health that is measured to see how a person is doing or whether a treatment works – for example, survival, memory or return to work.

PATIENT-REPORTED OUTCOME MEASURE (PROM): A questionnaire filled in by the patient themselves (sometimes with help) about their own symptoms, feelings, abilities or quality of life, without interpretation by a doctor or researcher.

RAYMOND-ROY OCCLUSION CLASSIFICATION: The most commonly used grading scale for aneurysm obliteration after coiling. It has three classes: Class 1, complete occlusion (the aneurysm is fully sealed); Class 2, residual neck (a small amount of filling at the neck); and Class 3, residual aneurysm (part of the aneurysm still fills with blood).

REBLEEDING: When an aneurysm that has already bled bursts and bleeds again. The risk is highest in the first hours and days after the first bleed, which is why aneurysms are usually treated as soon as possible. Rarely, rebleeding can also happen later if the aneurysm has not been fully sealed. Rebleeding and Aneurysm Obliteration together make up one of the six aSAH Core Domains.

RECURRENCE (RECANALISATION): When blood starts to flow back into an aneurysm that had been sealed, or the aneurysm grows back, some time after treatment – for example, if coils settle or squash down (compact). It is one reason why people often have follow-up scans.

RELIABILITY: Whether a measurement instrument gives consistent results – for example, the same score when it is repeated under the same conditions, or when it is used by different people. See also Inter-rater reliability.

RESPONSIVENESS: Whether a measurement instrument can detect a real change in a person's health over time, for example improvement during recovery.

SAH HOPE: Stands for Subarachnoid Hemorrhage – Helping measure Outcomes of Patients Effectively. SAH HOPE is the international group of doctors, researchers and people with lived experience working to establish and put into practice a Core Outcome Set for subarachnoid haemorrhage. SAH HOPE was formed when two earlier groups came together: aPOC (Aneurysmal Subarachnoid Hemorrhage Patient-Oriented Outcomes Collaborative), based in Canada, and MOSAIC (Making Outcomes in Subarachnoid Haemorrhage Patient Centred), based in Australia. The SAH HOPE logo was created by our lived experience partners.

SENSITIVITY: How good a test is at correctly finding the people who do have a condition. For example, if 100 people have a condition and a test correctly picks up 90 of them, its sensitivity is 90%. A test with high sensitivity misses very few cases.

SPECIFICITY: How good a test is at correctly ruling out the people who do not have a condition. For example, if 100 people do not have a condition and a test correctly says that 95 of them are clear, its specificity is 95%. A test with high specificity gives very few false alarms.

SUBARACHNOID H(A)EMORRHAGE (SAH): Inside your skull and around your brain there are layers of membrane. One of the layers is called the arachnoid layer. The space below it is called the subarachnoid space. A haemorrhage means that there is bleeding, so a subarachnoid haemorrhage is bleeding in the subarachnoid space that surrounds the brain. Most often, it occurs when a weak area in a blood vessel (aneurysm) on the surface of the brain bursts and leaks. The blood then builds up around the brain and inside the skull increasing pressure on the brain. When the bleeding is caused by a burst aneurysm, it is called an aneurysmal subarachnoid haemorrhage (aSAH).

SURVIVAL: One of the six aSAH Core Domains. It means whether a person is alive at a set time after their subarachnoid haemorrhage.

TIME POINT: The moment at which an outcome is measured – for example, at discharge from hospital, or 3, 6 or 12 months after the subarachnoid haemorrhage. A

Core Outcome Set can recommend when outcomes should be measured, as well as how.

VALIDITY: Whether a measurement instrument truly measures what it is meant to measure. See also Face validity and Content validity.

VASOSPASM: A narrowing of the arteries in the brain that can happen in the days after a subarachnoid haemorrhage. It can reduce blood flow to the brain and is one cause of delayed cerebral ischaemia (DCI).

WEB PROCEDURE (WOVEN ENDOBRIDGE): A type of endovascular aneurysm repair. A small, soft, ball-shaped basket made of fine braided wire is passed through a catheter and opened up inside the aneurysm. It blocks the flow of blood into the aneurysm at its neck, so that the blood inside clots and the aneurysm seals off. It is mainly used for aneurysms with a wide neck that sit where a blood vessel branches. It has its own grading scales for judging how well the aneurysm has been sealed.

WORKING GROUP: A small group of people with lived, clinical and/or research experience who focus on one Core Domain. Working group members review the candidate instruments for their domain and help recommend which should be included in the Core Outcome Set.