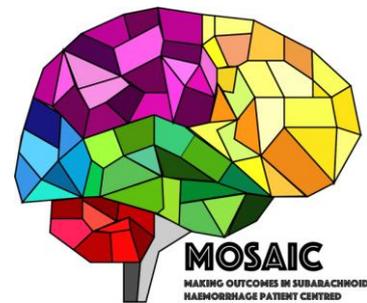


Brain aneurysm workshop

June 16th 2023



Why are we holding this workshop?

We are holding this workshop because we want to work with you to make brain aneurysm research better. We want to make sure that new research into subarachnoid haemorrhage from brain aneurysms measures what is most important to people who have had aneurysms, their families, health care professionals, and researchers.

What is the goal of this workshop?

At the end of this workshop, our goal is to have a list of no more than 7 to 9 of the most important things that researchers and doctors should measure when they test if a new brain aneurysm treatment works. We call these items *domains*, and our goal is to decide on a what is called a “Core Domain Set”.

What is a Core Domain Set?

A Core Domain Set is a list of domains that experts agree must be used to measure an illness or health condition in future research. The chosen domains must be important to all expert groups, including people who have the illness or health condition, researchers, and doctors or other health care professionals.

Why is it important to hold this workshop now?

It is important to hold this workshop because right now there is no standard way that researchers and doctors measure if a new treatment works. Creating a standard list could help researchers and doctors understand if a new treatment they are creating will help people who have an aneurysm.

Over the past few years, our research team has talked with hundreds of people who have had aneurysms, their families, health care professionals and researchers about what they think is most important after an aneurysm. This workshop is the final step in deciding the list of the most important things that researchers and doctors should measure in new research.

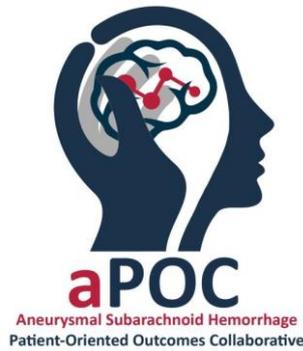
What will happen during this workshop?

The workshop will have two main parts.

In part 1, our team will introduce the top seven to nine domains that we have heard are most important from the process of talking with hundreds of people over the past few years. This list has four categories:

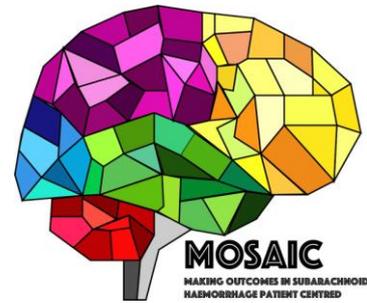
1. domains that must be included in all research,
2. domains that must be included in all research in some circumstances
3. domains that are important but optional.
4. domains we need to ask more questions about before we collect information on them.

We know that this list won't include everything that is important to everyone. The final list is only the most essential domains that all research **MUST** measure. Together, people in the workshop will vote on whether this list has the most important domains. If we agree, we move onto part 2. If we



Brain aneurysm workshop

June 16th 2023



do not agree we will vote on each domain on its own to decide if it should be classed as most important.

In part 2, attendees will split into smaller groups to talk about what each domain means, and we will try to agree on how it is defined.

Who will be at this workshop?

People who have had an aneurysm, their families, researchers, and doctors from around the world will take part in this workshop. Some people will join online and some will be in person. Everyone invited to the workshop is there as an equal partner in this process of agreeing what is most important. Most of the participants will be people with lived experience of brain aneurysm. Some of the participants will be doctors, some will be researchers. All have a unique perspective on what is important.

What do you need to do before the workshop?

Before you join us for the workshop, please watch the background videos we have prepared for this workshop. The links to the videos are in the email you received, on our [YouTube Channel](#) and here:

1. What is the goal of the workshop? 2 minutes long: <https://youtu.be/JusUYqQUyNO>
2. What is a core domain set? 2 minutes long: <https://youtu.be/askysD8knOE>
3. Why is it important to create a Core Domain Set for research of sub-arachnoid haemorrhages from brain aneurysm? 3 minutes long: <https://youtu.be/DSCxLbEqROk>
4. How will we decide a Core Domain Set for research of subarachnoid haemorrhage from brain aneurysm? 3 minutes long: <https://youtu.be/LyjQMB6jj7o>

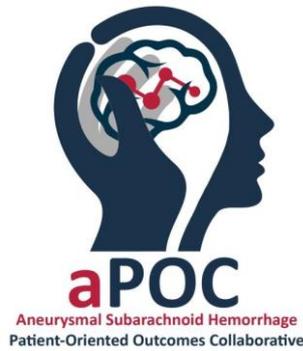
There is also a helpful short 3-and-a-half-minute long video from another group called [COMET](#) about the linked idea of Core Outcome Sets: <https://youtu.be/g1MZi2mzK1U>

We will send more information later this week, or the week after so please look out for further emails about the workshop.

Who can I contact if I have questions before, during, or after the workshop?

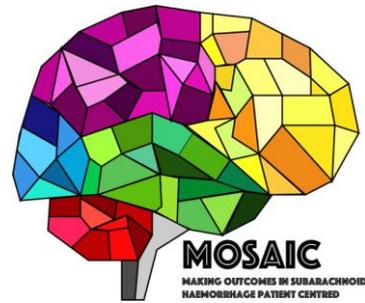
Before and after the workshop please contact Gordon Fernie at gfernie@ohri.ca.

During the workshop we will have a team of facilitators online and in person who can answer questions or provide feedback to both



Brain aneurysm workshop

June 16th 2023



Where can I find the published research this workshop is based upon?

Several research articles have been published. You can find them at the links below or on www.SAHCoreOutcomes.com/Publications/.

1. The case for a Core Outcome Set was made in a paper called Core outcomes for subarachnoid haemorrhage was published in The Lancet: [https://doi.org/10.1016/S1474-4422\(19\)30412-0](https://doi.org/10.1016/S1474-4422(19)30412-0)
2. The results from one of the domain ranking exercises (a Q-Sort) were published in an article titled “Prioritizing outcome measures after aneurysmal subarachnoid hemorrhage: A q-sort survey of patients, health care providers and researchers”. It was published in Frontiers in Neurology: <https://doi.org/10.3389/fneur.2022.1068499>
3. A consideration of “what” to measure in research of subarachnoid haemorrhage from brain aneurysm was made in an article called “Made to measure—Selecting outcomes in aneurysmal subarachnoid hemorrhage research”. This was published in Frontiers in Neurology: <https://doi.org/10.3389/fneur.2022.1000454>
4. Whether patient-reported outcomes were measured in past research of subarachnoid haemorrhage from brain aneurysm was reviewed in an article called “Do patient-reported outcome measures for SAH include patient, family, and caregiver priorities?”. This was published in Neurology: <https://doi.org/10.1212/WNL.0000000000006883>
5. The large number of outcomes measured in past research of subarachnoid haemorrhage from brain aneurysm was reviewed in an article called “A Systematic Review of Outcome Measures Employed in Aneurysmal Subarachnoid Hemorrhage (aSAH) Clinical Research.” This was published in Neurocritical Care: <https://doi.org/10.1007/s12028-018-0566-0>