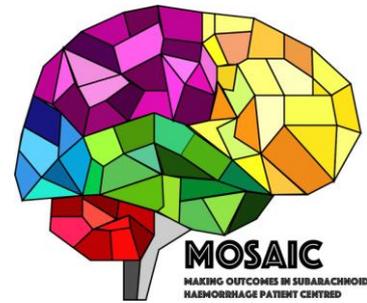


Brain aneurysm workshop

June 16th 2023

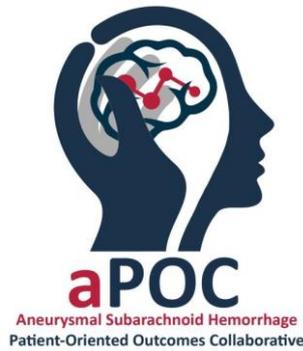


What is the goal of the workshop?

The goal of the workshop is to decide what should be measured and reported in future research of sub-arachnoid haemorrhage from brain aneurysms. We call these things to be measured “domains.” Ultimately, by the end of the meeting we would like to agree on the list of the most important domains. These lists are called “Core Domain Sets.” Right now, there is no “Core Domain Set” for aneurysm research, but researchers, clinicians, and patient advocacy groups have said that creating one should be a priority.

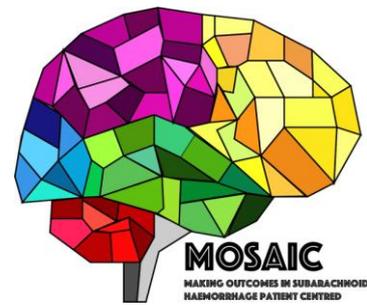
Core Domain Sets are created when multiple groups come together to decide which domains are most important. During this workshop, when deciding what is most important you should consider what is important for medical care AND in the lives of people who have had an aneurysm. In this case, we have invited people who have had aneurysms, their families, clinicians, researchers, funders, and policymakers to help create this Core Domain Set.

We look forward to working with you to decide on the Core Domain Set for brain aneurysm research.



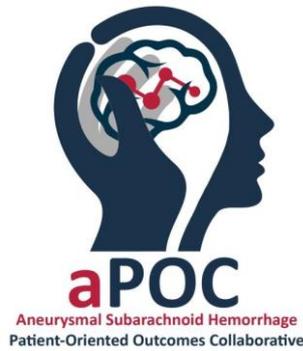
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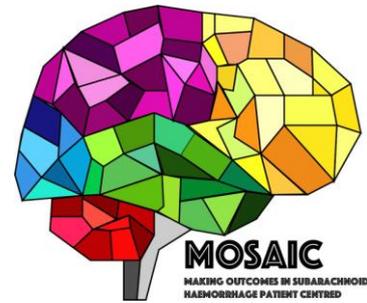
What is a core domain set?

- A domain is any milestone, symptom, characteristic or attribute that can be measured.
- In research, domains are used to decide what is measured during a study. Domains can be measured in different ways. Some examples include blood tests or imaging results, looking at how someone moves or does activities, looking for specific symptoms, or how people report their experiences of their health and quality of life. Domains can also include measurements of the resources that are used and even if, and how long, people survive.
- A Core Domain Set is the list of domains that experts agree must be used to measure an illness or health condition. Each illness or health condition can have its own Core Domain Set. The chosen domains must be important to all expert groups. Expert groups include people who have the illness or health condition, their families, researchers, clinicians, as well as research funders and policy makers.



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Why is it important to create a Core Domain Set for research of sub-arachnoid haemorrhage from brain aneurysms?

First, 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.

What do Core Domain Sets do?

Core Domain Sets help make sure that new research measures what is important to people.

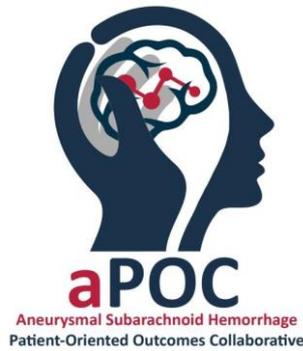
How are Core Domain Sets different from other research?

Core Domain Sets are created when different expert groups come together and agree on what should be measured. Importantly, people who have the illness or health condition and their families are included in this process as experts. This is because they are the ones most affected by the illness or health condition and who will benefit the most from new treatments.

Creating a Core Outcome Set for research of sub-arachnoid haemorrhage from brain aneurysms is important because:

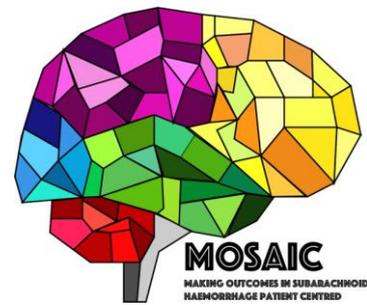
- 1) Right now, it is hard to compare brain aneurysm studies because each study measures different things. This can lead to research findings being wasted because the results cannot be added to the findings of other studies.
- 2) Without a Core Outcome Set, researchers and doctors may measure the wrong information or measure the right information at the wrong time. They may also have to use tests created for other health conditions that miss details specific to brain aneurysms.
- 3) Lastly, many brain aneurysm studies have not included the perspectives of people who have had an aneurysm or their families. This may mean that new treatments do not consider what is important to them.

These are just a few reasons why deciding on the Core Domain Set at our consensus workshop on June 16 is important. Please listen to our short clip entitled “How will we decide a Core Domain Set for research of sub-arachnoid haemorrhage from brain aneurysms?” to learn where the domains we will discuss at the consensus workshop came from.



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How will we decide a Core Domain Set for research of sub-arachnoid haemorrhage from brain aneurysms?

At the workshop, we will decide the Core Domain Set together with you and other invited experts. These experts include people who have had a brain aneurysm and their families, researchers, doctors and other health care professionals.

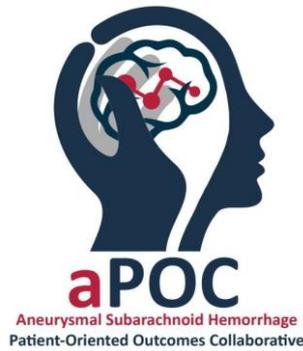
Our research team has done a lot of work over the past few years to prepare for this meeting. This includes:

1. Looking at completed studies to see what information is measured in brain aneurysm research right now. From this, we know that many different things are measured, and that things important to patients are not always included.
2. Holding a meeting in 2019 with researchers, doctors, people who had an aneurysm, and their families. It was at this meeting that everyone decided that we needed to create a Core Outcome Set for brain aneurysm research.
3. Speaking with hundreds of people including people who had had an aneurysm, researchers, and doctors. They suggested over 100 domains that could be included in a Core Domain Set. To choose the domains that we will discuss at this meeting, we asked people to rank the domains from most to least important. We will be discussing the top 7 to 9 of these at our workshop and deciding if they should be the Core Domain Set.

At our consensus workshop on June 16th, we are going to discuss:

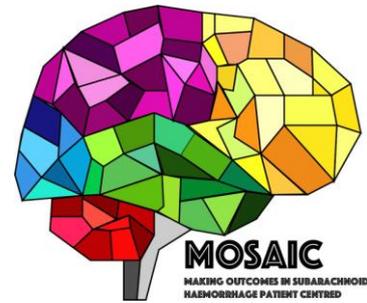
- 1) if the list we created through this background work is complete, and,
- 2) Create definitions for each of the domains we include in the Core Domain Set.

We need your help to achieve this goal.



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GLOSSARY OF TERMS

aPOC: Stands for Aneurysmal subarachnoid hemorrhage Patient-Oriented Outcomes Collaborative. They are the group of doctors, researchers and people with lived experience based in Canada who have been researching measures that address patients' symptoms and concerns after subarachnoid haemorrhage.

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.

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: A Core Outcome Set includes decisions on when and how to measure the Core Domains.

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

MOSAIC: Stands for Making Outcome in Subarachnoid Haemorrhage Patient Centred. They are the group of doctors and researchers based in Australia who have been researching subarachnoid haemorrhage to make it more patient centred.

OMERACT: stands for Outcome Measure 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. The development of the Core Domain Set for subarachnoid haemorrhage from brain aneurysm uses the processes developed by OMERACT.

SUBARACHNOID HAEMORRHAGE: 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.