Code of Conduct

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This code of conduct defines principles, values, standards, and rules of behavior that guide the decisions, procedures and systems of the “Swiss Study On aneurysmal Subarachnoid hemorrhage” Group in a way that contributes to the welfare of its stakeholders and respects the rights of all constituents affected by its operations.

Definitions & Abbreviations:

AB = advisory board

aSAH = aneurysmal subarachnoid hemorrhage

DM = data manager

GA = general assembly

GCP = Good Clinical Practice

HRA = Swiss Human Research Act

IA = intracranial aneurysm

ICH = International Conference on Harmonisation

IMK = Institut für Medizin und Kommunikation

LSC = local study contributor

PI = principal investigator

PR = website/public relations

SC = Swiss SOS coordinator

SSNR = Swiss Society of Neuroradiology

SSNS = Swiss Society of Neurosurgery

SRC = Scientific Review Committee

SSC = Study Steering Committee

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1. Name

The name of the group shall be “Swiss Study On aneurysmal Subarachnoid hemorrhage”, hereafter referred to as “Swiss SOS”.

2. Definition

The Swiss SOS is an interdisciplinary group that concentrates on research on aneurysmal subarachnoid hemorrhage (aSAH) and intracranial aneurysms in general. The group founded a nationwide, multicenter research project in 2008 as bottom-up initiative, which has evolved to be a prospective, institutional-review-board approved database containing continuous anonymous information on patients diagnosed with aSAH in Switzerland.

3. Aims

The aims of the Swiss SOS are

a. to monitor aSAH epidemiology in Switzerland
b. to measure and control the quality of aSAH treatment in Switzerland
c. to provide a network for and foster clinical research and collaboration between Swiss Centers and disciplines involved in the management of aSAH.
d. to guide the future direction of aSAH management in Switzerland.

4. Membership

Membership in the Swiss SOS shall take two forms:

a. institutional membership
b. individual membership

<u>Institutional membership</u>

1. is open to departments in Switzerland involved in the treatment of aSAH patients. For institutional members, it is required to pay the annual institutional membership fee.
2. The annual institutional membership fee is set at 500 (five hundred) CHF but can be adjusted by the General assembly (GA), if deemed necessary.

<u>Individual membership</u>

1. is possible as full or associate individual membership.

a. Full individual membership

is open to any physician in good standing involved in the treatment of aSAH patients (neurosurgeon, neuroradiologist, neuro-intensive care physician, neurologist, neurorehabilitation physician, etc.), who is interested in contributing to the collaborative to achieve its aims and is willing to abide by the rules of the group.

Full individual members are employed at a department that has institutional membership status. Full individual members have the right to vote at the general assembly and shall pay the annual full individual membership fees.

The annual full individual membership fee is set at 30 (thirty) CHF, but can be adjusted by vote during the general assembly, if deemed necessary.

b. Associate individual membership

is open to any person in good standing who is interested in contributing to the collaborative to achieve its aims and is willing to abide by the rules of the group. We anticipate this would include

physicians not employed at a department that has institutional membership status, medical students and allied health professionals.
Associate individual members do not have the right to vote at general assembly and shall pay the annual associate individual membership fee.
The annual associate individual membership fee is set at 15 (fifteen) CHF, but can be adjusted by the general assembly, if deemed necessary.
People elected as part of the Advisory Board (AB) become associate individual members but are exempt from the annual membership fee.

Registration & Termination of membership

a. Swiss SOS membership is recorded by the Institute for medicine and communication Ltd. (IMK), who can be contacted with regards to registration & termination.
b. A successful registration
   - As institutional member requires positive vote by the general assembly (GA) & evidence of membership fee payment. An additional institutional membership within an already registered center requires the agreement of the Swiss SOS Chief Coordinators & evidence of membership fee payment.
   - As full individual member requires evidence of an institutional email address from one of the centers that are registered as institutional members, evidence of membership fee payment and a recommendation letter written by the local principal investigator (PI) of the Swiss SOS study.
   - As associate individual member requires evidence of membership fee payment.
c. Voluntary termination of Swiss SOS membership shall be made by contacting the IMK; payed membership fees will not be reimbursed.
d. The Swiss SOS may, by resolution passed at the general assembly (GA) thereof, terminate or suspend the membership of any institution (institutional membership), full or associate individual members if the parties conduct is prejudicial to the interests and objectives of the Swiss SOS or if they do not comply to the Registration & Termination rules. The principal investigator (PI) of the institution, or the individual full/associate member shall have the right to be heard by the GA before the final decision is made, respectively. There shall be a right of appeal to an independent arbitrator appointed by the Swiss SOS Coordinators (SCs).

5. Positions, organs and responsibilities

a. General Assembly (GA)

Composition & Definition: The general assembly (GA) is composed out of all Swiss SOS individual members. The general assembly (GA) is the highest authority and the organ responsible for taking important decisions within the Swiss SOS.
Roles: The general assembly (GA) elects the positions within the Swiss SOS, decides on membership issues, regulate the rules of the data management platform and of the modifications to the variables/dataset, approves the yearly budget allocated to data management and the various Swiss SOS activities.
Meetings: The general assembly (GA) meets at least once per year, normally at the time of the Swiss Society of Neurosurgery (SSNS) and/or Swiss Society of Neuroradiology (SSNR) (joint) meeting. The general assembly (GA) can statute on the number and venues of meetings. Furthermore, electronic meetings or votes can be organized (see below).
Organization & Transparency: The general assembly (GA) is organized by the IMK in close collaboration with the Swiss SOS Coordinators (SCs) and should be announced via email to all

individual members at least 2 months in advance. Meeting dates and locations shall also be exposed on the Swiss SOS website. Votes on important decisions must be listed on the agenda and this agenda must be distributed via email among the individual members at least one week prior to the general assembly (GA). All general assembly (GA) meetings must be recorded in minutes; those minutes shall be distributed to all Swiss SOS individual members per email within 21 days after the meeting.
Voting: Decisions are taken by open ballot with simple majority and votes of full individual members. Only the votes of full individual members that are physically present at the GA meeting count. Electronic votes count for virtually (electronically) conducted meetings only. If there is a tied vote, then the vote of the Swiss SOS Coordinators (SCs) shall count twice. Individual decisions can be taken by secret ballot, should this be requested by at least one full individual member.

b. Swiss SOS Coordinators (SCs):
Composition & definition: The Swiss SOS Coordinators (SCs) are five people, affiliated with different departments that hold institutional membership status. Preferably the Swiss SOS Coordinators (SCs) should also represent different medical specialties. The Swiss SOS Coordinators (SCs) are responsible for upholding the present Swiss SOS code of conduct. As "board of the Swiss SOS", the Swiss SOS Coordinators (SCs) should work closely together (personal/virtual meetings 3-4 times per year). They have the obligation to act in the interest of the Swiss SOS as a whole and are responsible for the long-term success of the Swiss SOS.
Roles: The Swiss SOS Coordinators (SCs) are responsible for organizing the general assembly (GA) (or any other meeting on request) & composing the minutes of those meetings together with the IMK. They serve as primary contact for and coordinate all affiliated structures of the Swiss SOS (including data management (DM), Advisory Board (AB), website/public relations (PR), Scientific Review Committee (SRC) & center PIs).
Terms of service: Swiss SOS Coordinators (SCs) are full individual members with (vast) experience within the group, e.g. by having served in affiliated Swiss SOS structures before. They can be proposed by any full individual member and are elected by the general assembly (GA). Swiss SOS Coordinators (SCs) are active for a 3-year term and can be re-elected once (max. 6-year term).
First-time election: For the initial board of the Swiss SOS, all department chairs of the neurosurgical and neuroradiological departments of Kantonsspital Aarau, Universitätsspital Basel, Inselspital Bern, Hôpitaux Universitaires de Genève, CHUV Lausanne, EOC Lugano, Kantonsspital Luzern, Kantonsspital St.Gallen and Universitätsspital Zürich are each asked to propose up to two people for this position. The list is collected by the IMK and distributed along with the agenda about one week prior to the general assembly (GA). At the general assembly (GA), each neurosurgical and neuroradiological department (listed above) can vote for up to five different people on the list. The five people with most votes will form the first board as Swiss SOS Coordinators (SCs).

c. Advisory Board (AB)

Composition & definition: People that were active as members but stepped down from their active duty or senior physicians with neurovascular focus from the Swiss SOS centers with institutional membership may become associate individual members, and hence part of the advisory board (AB).

Roles: Advisory board (AB) members are entitled to make suggestions pertaining to the strategy and long-term success of the group, but they have no decisional (voting) power.

Terms of service: Advisory board (AB) members are proposed by the Swiss SOS Coordinators (SCs) and are elected by the general assembly (GA). The advisory board (AB) membership is limited to 10 years.

d. Principal investigator PI

Preamble: The role of the principal investigator (PI) for a research project is defined by the International Conference on Harmonisation of technical requirements for registration of pharmaceuticals for human use (ICH) and their guidelines for Good Clinical Practice (GCP; https://ichgcp.net). This definition is also valid for the Swiss SOS study, but in addition the following code of conduct should be respected by each center principal investigator (PI).

Composition & definition: The principal investigator (PI) role is fulfilled by one person from the neurosurgery and/or one from the neuroradiology department at each contributing Swiss SOS center with institutional membership. The principal investigator (PI) must be full individual member of the Swiss SOS. In case of two PIs, each department (neurosurgery and neuroradiology) must also hold its own separate institutional membership of the Swiss SOS, independent of the individual memberships of the PIs. The position of the PI is chosen in good faith by the senior neurovascular physicians of the neurosurgery and neuroradiology departments at each site. The principal investigator (PI) has to be formally suitable to conduct research according to GCP guidelines.

Roles: For the Swiss SOS project, the principal investigator's (PI) responsibility is to ensure that continuous, high-quality data is provided from his/her center and that all ethical and legal requirements (Swiss Human Research Act (HRA)) are met. If only one PI is appointed, that PI assumes overall responsibility for the entire center, covering both neurosurgery and neuroradiology departments. In centers with two PIs, each PI is responsible for the quality and completeness of data from their respective department (neurosurgery or neuroradiology), and both PIs share overall center-level oversight. The principal investigator (PI) leads the team of local study contributors (LSCs) and is responsible for the quality and completeness of data from their own center or department. The principal investigators (PI) are also the persons to be informed by the Swiss SOS Coordinators (SCs) about all on-going activities and issues. It is the responsibility of the principal investigator (PI) to share this information with the chairpersons of involved departments and the local team, including local study contributors (LSCs) and research nurses/coordinators as applicable.

Terms of service: The principal investigator (PI) position is not limited in time. Membership fees for the center are calculated based on the required institutional memberships: one PI equals one institutional membership fee; two PIs equal two institutional membership fees (one for neurosurgery and one for neuroradiology). The individual membership fees of the PIs (and other involved persons) are separate and remain unaffected by this. If a center transitions from two PIs to one PI (or vice versa), the membership fee shall be adjusted pro rata from the date of the change, and the Swiss SOS Chief Coordinator must be notified in writing within 30 days.

e. Local study contributors (LSC)

Preamble: The role of the local study contributors (LSCs (=investigators)) for a research project is defined by the ICH and their guidelines for GCP (https://ichgcp.net). This definition is also valid for the Swiss SOS study, but in addition the following code of conduct should be respected by each local study contributor (LSC).

Composition & definition: Local study contributors (LSCs) typically include neurosurgeons, neuroradiologists and other people active in the care and research of aSAH patients at each center. Local study contributors (LSCs) are elected by the local principal investigator (PI). Local study contributors (LSCs) have to be formally suitable to conduct research according to GCP guidelines. Local study contributors (LSCs) must either be full or associate individual members of the Swiss SOS. Five local study contributors (LSCs) per department and a maximum 10 local study contributors (LSCs) per institution are allowed at a time.

Roles: Local study contributors (LSCs) help the principal investigator (PI) collect and validate Swiss SOS data from their center. They support the principal investigator (PI) with other tasks, as needed.

Terms of service: There is no maximum length of service.

f. Data Manager (DM)

The data manager (DM) is a person not otherwise implied in the Swiss SOS (neutral character) with sufficient knowledge in the scientific and legal aspects of data collection. The data manager (DM) manages the Swiss SOS database in keeping with Swiss ethical and legal requirements. The data manager (DM) should ideally be affiliated with a Clinical Trials Center or Unit. The data manager (DM) is elected by the general assembly (GA). There is no maximum length of duty. The data manager (DM) should ensure that each contributing center should have constant and full access to its own center-specific data on simple request by the center principal investigator (PI). To obtain data from other centers, however, a formal request must be granted (see SSC section below).

g. Scientific Review Committee (SRC)

The Scientific Review Committee (SRC) is composed of four full individual members, preferably from different centers and including different medical specialties. Scientific Review Committee (SRC) members are elected by the general assembly (GA), active for a 3-year term and can be re-elected once. The first important role of the Scientific Review Committee (SRC) members is to review project proposals, abstracts and scientific articles before those are distributed within the larger Swiss SOS network and to thereby increase the quality of Swiss SOS projects and publications. Scientific Review Committee (SRC) members should provide constructive and fast feedback to the person or group who submitted the work (usually within 2 weeks after complete and successful submission).

The second important role of the Scientific Review Committee (SRC) members is to review the completeness and quality of the Swiss SOS data from each center and provide feedback to the local principal investigator (PI). Once the data quality is deemed sufficiently high by the Scientific Review Committee (SRC), one “locked dataset” for each calendar year will be generated from the whole Swiss SOS data, which can be used for approved Swiss SOS studies.

h. Website and Public Relations (PR)

One or two designated PR people are elected by the general assembly (GA) for a 3-year term and can be re-elected. These persons work in close collaboration with the IMK in managing the

Swiss SOS website content, update this website regularly and create public visibility of the Swiss SOS (e.g., social media). Furthermore, they serve as contact for external requests. The PR persons work in close collaboration with the Swiss SOS Coordinators (SCs).

i. Study steering committee (SSC)

Each full or associate Swiss SOS member can propose studies to be conducted with the Swiss SOS dataset. For those studies, the member shall compose a team, which is hereafter referred to as "study steering committee" (SSC).

The process and procedural steps for conducting research with Swiss SOS data originating from more than one center is detailed in the document "Procedure for multi-center research proposals based on data in the Swiss SOS registry".

6. Publication and ownership of data

The general authorship guidelines for research with Swiss SOS data originating from more than one center is detailed in the document "Procedure for multi-center research proposals based on data in the Swiss SOS registry".

7. Collaboration with third parties

Sharing of Swiss SOS data originating from more than one center with external third parties is only possible after a proposal with defined conditions has been reviewed by both the SRC & SCs, and after favorable vote at the GA.

8. Alterations on the present Code of Conduct

a. Proposals for amendments to the present Code of Conduct must be delivered to the five SCs in writing. The SCs in conjunction with all PIs shall then decide on the date of a dedicated meeting to discuss the proposals, giving notice at least 21 days in advance.
b. Any changes to the present Code of Conduct must be agreed by at least two thirds of those members present and voting at the next GA.

9. Adoption of the Code of Conduct

This Code of Conduct has been checked and voted on by the chairs of the department of neurosurgery and neuroradiology via online votes and finally approved as of February 18th, 2021. The Code of Conduct will be presented at the general assembly (GA) on March 15th, 2021. The Code of Conduct has been revised and approved by the GA on October 30th 2026.