

Agenda Swiss SOS Meeting August 2017



Location: KSA am Bahnhof, Room no. 1.116/117

Time: Wednesday, 09.08.2017, 17:00h - 20:00

Present:

M.N.Stienen, R.Maduri, D. Bervini, D.Zumofen, J.Fandino, C.Fung, S.Marbacher,
D.D´Alonzo, B.Schatlo, P.Bijlenga(Phone), J.K.Burkhardt(Phone)

Absent: M.Seule (excused)

1. Welcome

2. Reflection on the status quo

It was uniformly stated at the beginning of the meeting that the way the Swiss SOS was handled until now was fairly good. However, now a certain structure is required to be able to grow. Donato D´Alonzo cited the need to improve data quality further to ensure definitions and ways to acquire data are uniform. Javier Fandino proposed to introduce bylaws to regulate responsibilities and membership within the group.

R.Maduri in turn cautioned against blowing up the structure to a point where functionality is impaired. C. Fung cautioned against overregulation when we only have few centers. S.Marbacher raised the issue of abstracts being submitted without prior notice and suggested a review panel for publications. Other raised points included the role of neuroradiology and the need to raise funds.

3. Future structure of the Swiss SOS

Several points were subsequently raised. Membership, committees and biannual meetings were key points which will need to be filled with content. M.N.Stienen had prepared an organigram of a structure which included several distinct roles made up by standing committees and temporary taskforces.

a. Steering committee (SC)

To define direction and oversee day-to-day function

- b. Scientific Review Panel (SRP)
To evaluate and direct research activity, review abstracts and papers before distribution to the Swiss SOS community
 - c. Budget and Development Panel (BDP)
To oversee efforts to obtain funding and act as a treasurer
 - d. Taskforce Lucerne
Temporary group ensuring the transition of the new center to the group including secutrial access and maintenance of follow-up protocols in the early phase
 - e. Taskforce Neuroradiology
To ensure smooth integration of neuroradiological data into the current platform
 - f. Taskforce Neuropsychology
To maintain oversight over neuropsychological involvement
 - g. Local Principle Investigator
The local PI is the first respondent for a center's activity and for contributions to studies.
 - h. Local study contributor
With defined activity in the local hospital.
4. The suggestion to formalize the structure, invest a steering committee which is appointed by the PIs and to define its responsibilities. A scientific committee should ensure which studies are promoted and to maintain oversight over research activities. An advisory board should further serve to provide council and guidance.

5. Other relevant points (all) – 45 min

- a. Submission of any kind of Swiss SOS data (abstracts and papers)
The group agreed to adopt a practice of defensive abstract submission. This entails withholding submission of abstracts to a scientific meeting until a manuscript is ready for submission and approved by the scientific review committee. This should ensure that authorship issues, quality of data and writing and conflicts of interest regarding research topics have already been dealt with.
- b. Authorship and contributorship of Swiss SOS collaborators
The group is growing and may potentially include collaborators from other disciplines as well as investigators at multiple levels, i.e. PI, data collection, committee members etc. MN Stienen suggested a detailed definition of

authorship which takes into account these levels of involvement. Ultimately, the scientific research committee (globally) and the PIs (locally) ensure equitable consideration of top-line contributions. The list of collaborators will be maintained and updated regularly (D Zumofen).

- c. Philippe Bijlenga raised the point that in the future, trial data should be transparent. He suggested to collect data into an open access database. This suggestion was met with hesitance – a potential solution would be to leave a timelag of 2 to 5 years before open data “release” to allow for prior usage within the group.
- d. Taskforce data restructuring.
Since multiple projects will require additional data points and potentially new visits including new disciplines, a data restructuring taskforce may be necessary. However, since this will depend on each project we agreed to modify database structure only after project approval by the scientific committee and to do this on a project-by-project basis. The current strength of the data collection is based on its simplicity.
- e. Adding / modifying current data collection?
Multiple projects were discussed. It was proposed to delegate the more detailed discussion of these issues to the Development Panel of the Swiss SOS that is to be created
 - i. NIH/NINDS SAH common data elements (CDE) project
 - ii. Long-term aneurysm occlusion (recanalization/retreatment/rerupture)
 - iii. Neuropsychology (MoCA as recommended outcome measure by the CDE project)
 - iv. Return to work (CDE CRF on return to work)
 - v. Angio-negative SAH patients
 - vi. Sophisticated radiological data (collaboration with neuroradiologists to the Swiss SOS?)
- f. Data Capturing tool – Secutrial vs. RedCap vs. other:
At the discretion of a future committee (e.g. data quality/monitoring/scientific committee)

6. SwissNeuroFoundation / AneurysmDataBank (Bijlenga) – 10 min

P.Bijlenga is working on establishing an integrated data platform for clinical and research application which is conform with Swiss Public Health Network (SPHN). He asked whether Swiss SOS was willing to participate in a short-term call for proposals for funding. He will distribute further details via email.

7. Next meeting

Separate Meetings should be held to

- 1) work out a proposal for bylaws / agree on a draft (PIs)

2) fill the positions described above (committees)

These meetings will be organized on the PI level in the next weeks.