

# Registry Meeting Minutes

March 2017, HVS Monaco

---

## Agenda

### I. General Meeting - Thursday 2nd March from 12.00 to 13.30

---

Members present: Hanneke Takkenberg (Erasmus MC), William F. Northup (Cryolife), Elaine Tseng (USCF), Ismail Bouhout (Montreal Heart Institute), Peter Verbrugghe (UZ Leven), A.L. Gökalp (Erasmus MC), Diana Aicher (Saarland), Jan Vojacek (Hradec Kralove), Ismail El Hamamsy (Montreal Heart Institute), Irem Karliova (Homburg/Saarland), Agnès Lamouliatte (Cryolife), Jean Marc Marnette (CHR Namur), Ebuzer Aydin (Istanbul Medeniyet University), Simon Body (Brigham, Boston), Bo Yang (University of Michigan), Bardia Arabkhani (Leiden), Mostafa Mokhles (Erasmus MC), Frederiek de Heer (AMC), Emmanuel Lansac (Institut Montsouris), Stéphanie Lejeune (Institut Montsouris)

#### 1. AVIATOR UPDATE

---

55 centers with 4301 patients enrolled. We need to enroll more patients with valve replacement to have a more representative population (currently, we have only 7% with valve replacement in the Aviator database). We have to recruit more centers who perform the David technique. Currently the Yacoub procedure is in the majority of all VSRR procedures (14% of reimplantation and 86% of remodeling)

#### 2. PATIENT SUMMARY

---

It is available online in "summary" part, for each patient. Since it is a clinical oriented database, Aviator extract directly positive items into a pdf file which resumes patient case. An echo follow up is also available and summarized in one table.

#### 3. EMPOWERING THE PATIENT

---

With the aviator data base CleanWeb support system, patients will be able to be active in the FU process by answering to emails with questionnaire and in the near future with phone applications.

## 4. MULTICENTER PROPOSAL

---

- We plan to submit the following paper, written by Frederiek de Heer:
- AVIATOR registry: an open international cohort to evaluate medical and surgical outcomes of Aortic Valve Insufficiency and Ascending Aorta Aneurysm.
- This paper describes the cohort of interest, the database features, the organizational structure and the rules to initiate and perform multicenter analysis.
- In order to get more feeling which scientific questions could be answered by the collected data thus far, we will present the follow up completeness divided by clinical follow-up and echo follow-up at the next meeting (EACTS, October).
- A multicentric analysis of AV repair using external aortic ring annuloplasty technique cohorte was proposed (PI Emmanuel Lansac) to the scientific committee and discussed during the meeting. Jochen Schafers group suggested to include in this study the annuloplasty stitch patients which represent different study with a comparative group. It was consider as a good idea that needs to be precise in a protocol to be submitted to the scientific committee.
- Anyone who wants to do a multicentric analysis need to inform the scientific committee with the procedure below:
  - Submit the proposal to [AVIATOR@heartvalvesociety.org](mailto:AVIATOR@heartvalvesociety.org) (suggested by Hanneke Takkenberg for more transparency). In the near future, we will facilitate this on the Aviator website.
  - The proposal will be reviewed by the scientific committee and discussed during the next Aviator meeting.

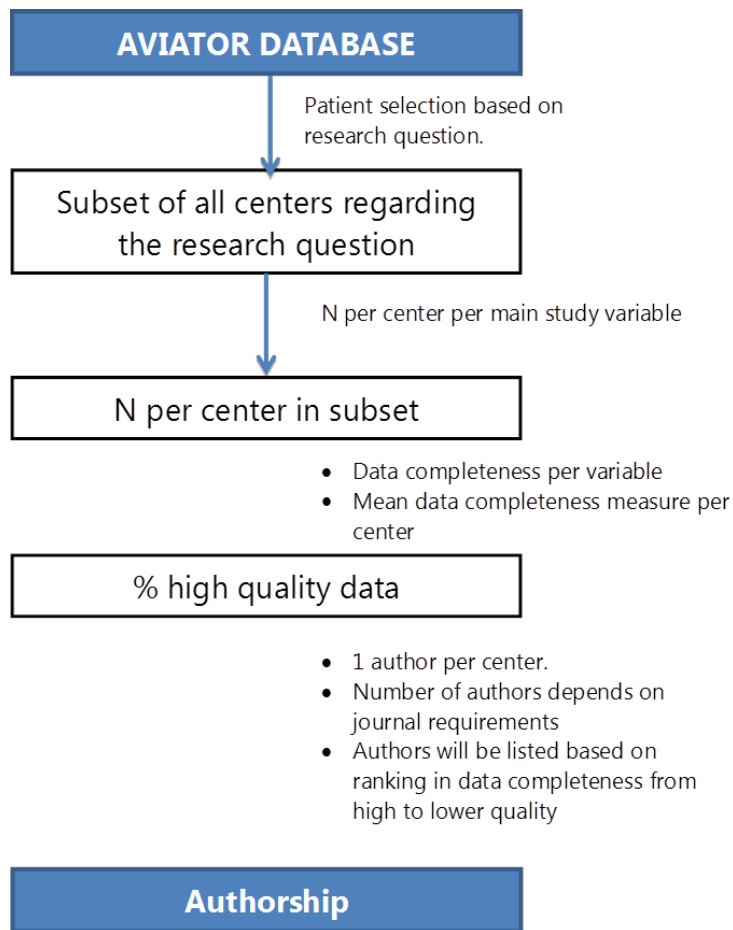
## 5. AUTHORSHIP

---

During the meeting there was still debate about who will be listed in between the first and last author. We need to find a balance between high and low volume centers. We just can't ignore the high volume centers as it will be likely for them to stop with data entry. On the other hand low volume centers are important as well for generalizability. During the meeting we agreed to focus on data completeness for the selection and ordering of authors in between. There was consensus for the proposed rule for first and last authorship.

Currently it is stated as follows in the concept paper: *"First and second authorship is for the person who did the job (ideally young investigators). Last authorship is for the PI of the proposal. Authors in between (one per center) are those who contributed to the data analysis and/or included data to the specific research question and will be listed based on ranking in data completeness from high to lower quality. Other investigator from contributing AVIATOR centers will be acknowledged."*

Proposed framework for listing the in-between authors:



Appendix: All other investigators from participating centers who contributed data to the research question.

## II. Medical Registry Meeting - Friday 3th March from 12.00 to 13.30

---

Members present: Alain Berrebi (Institut Mutualiste Montsouris/HEGP), Jean-Louis Vanoverschelde (Cliniques Universitaires Saint Luc), Peter Verbrugghe (UZ Keuven), Giorgio Franciosi (Cardiocentro Ticino), David Kalfa (Columbia university), Paolo de Siena (Pavia Italy/Leeds UK), Irem Karliova (Homburg/Saarland), Jochen Schäfers (Homburg/Saarland), Diana Aicher (Saarland), Bo Yang (University of Michigan), Marie Annick Clavel (Quebec Heart Institute), Alexis Theron (CHU Timone, Marseille), David Messika Zeitoun (Bichat, Paris), Francesco Grigioni (University of Bologna), Maurice Sarano (Mayo Clinic), Frederiek de Heer (AMC), Emmanuel Lansac (Institut Mutualiste Montsouris), Stéphanie Lejeune (Institut Mutualiste Montsouris)

The aim of this meeting was to talk about the Aviator Medical Registry and to finalize the CRF form in order to send it to production. This registry permits to evaluate patients who haven't reached the surgical guidelines yet and to follow them until the surgery. The Aviator Medical registry will be available online in few months. The finalized CRF form will be sent very soon to cardiologists who were presents at the meeting, other key opinion leader in the field and to the scientific committee for the final validation.