

# Registry Meeting Minutes

17-18 March 2016, HVS New York

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The AVIATOR group had 3 working session:

- I. General meeting AVIATOR
- II. AVIATOR medical task force meeting
- III. Friendly Surgical Report

## I. General meeting AVIATOR (Thursday 17<sup>th</sup> march – 7.15 am)

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Members present: Pallav Shah, Alain Berrebi, Jan Vojacek, Emilie Bollache, Gebrine Elkhoury, Igor Rudez, Rita Milewski, Hanneke Takkenberg, Hans-Joachim Schäfers, Benjamin Van Boxtel, Laurent de Kerchove, Emilie Bollache, David Messika Zeitoun, Philippe Pibarot, Francesco Gnigioni, Mauro Del Giglio, Yolanda Kluin, Frederiek de Heer, Emmanuel Lansac, Stéphanie Lejeune

## Agenda

### 1. AVIATOR Surgical Registry update

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The new online Aviator database started at the begin of December 2015. Aortic valve repair, valve sparing root replacement or valve replacement (control group) can be included.

All data from each center who participated in the Julius Center database have been migrated to the new database.

Currently, there are 30 participating centers listed in the new database, of which 21 centers have enrolled a total of 969 patients.

For centers who haven't included patient yet: One can start enrolling patients directly online (case by case) or one can decide to upload existing patient from a local database to the Aviator Registry (batch upload).

Both options take time. The choice between both options depends heavily on the local setting (volume, project assistance, local database with 'Aviator' variables). There is now a manual available how to perform the batch upload.

The clinical summary is available online, but is still in development It is already possible to download the summary for each patient and get on overview of the information entered in the registry on patient level. The clinical summary does not cover all variables yet. The more complete version will be published very soon.

## 2. AVIATOR Medical working group (ex AIDA)

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Include the same population as AVIATOR surgical but in the pre-operative period for patients who did not reach operative criteria.

A task force was set up in order to finalize the selection of variables of the CRF. During the meeting, the following surgeons and cardiologist volunteered: Rita Milewski, Laurent de Kerchove, Emilie Bollache. (meeting in the afternoon, see below)

## 3. AVIATOR Kids

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Aviator kids will be in addition to the other two registries. . People who could be involved in the project construction are: Jolanda Kluin, Hans-Joachim Schäfers, Olivier Raisky. Specific items to the pediatrics population will be included to the two main registries (Aviator medical and Aviator surgical)

## 4. Task force to do the work : “Trio-Team”

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In order to do the work that needs to be done for a successful AVIATOR registry and research network and in order to bring new people and give visibility for future scientific committee members, we suggest creating specific task force for “trio-team” which ideally for each topic include a cardiologist, a surgeon and a scientist

Several

- Friendly surgical report and statistic on line : Frederiek de Heer and Rita Milewski
- Protocol and data base documents : Frederiek de Heer and Rita Milewski
- Communication (website, communication with other scientist society and hospital or research team to join the group and registry )
- Financial issue : Jolanda Kluin

If you are willing to help to do the job by joining one of these task forces, please let us know either by answering to this mail or by choosing online soon when Shelagh from the HVS will send you a specific mail for this issue.

## 5. Internal Regulation of Aviator working group

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One member of each team has to become a member of the Heart Valve Society and then has the right to vote for electing the scientific committee. It was decided that the scientific committee will be renewed every 3 years starting in 2018 at the annual HVS meeting.

*Scientific committee*

- 6 members including at 2 cardiologists, 2 surgeons, 2 scientists. It will be a co-chaired (avoiding two people from the same specialty), 1 secretary and 3 members.
- Members of the scientific committee will serve for 3 years not renewable straight away. After another terms of 3 years it is possible to be candidate for one more mandate.
- 2 co-Chairs and secretary will remained in the scientific committee for one year after the terms of their mandate in order to ensure continuity
- electronic vote will be before the annual meeting every 3 years with prior announcement of the election

## II. AVIATOR medical task force meeting (Thursday 17th March – 17.30 pm)

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Members present: Rita Milewski, Emmanuel Lansac, Frederiek de Heer, Stéphanie Lejeune, Emilie Bollache, David Messika Zeitoun, Philippe Pibarot, Francesco Gnigioni, Mauro Del Gighio, Yolanda Kluin.

The name AIDA was given already to an international trial (registered in Clinicaltrials.gov).. It was suggested to rename it “AVIATOR Medical Registry” as it was originally, in order to have consistency between the several registries since they refer to the same population (AI and/or aneurysm potential candidate for valve repair).

All existing and future registry will be part of AVIATOR:

- Aviator Surgical (active)
- Aviator Medical in process (old AIDA)
- Aviator Kids (in project)

This meeting helped to work on the medical Registry CRF and review it on word document. This document will be sent to group in order to have a finalized version of the CRF as soon as possible.

Biologics markers: They are not really useful yet on the medical Registry but could be useful for the future.

Francesco Grigioni talked about the experience of the MIDA registry editorial policy: “All the investigators should meet every six months to update and be updated concerning the status of the ongoing projects. The projects will be assigned as follows. All participating Centers are entitled to present the request to test a specific hypothesis during the meetings. The other investigators are invited to provide comments and suggestions to improve the quality of the projects presented. In case of duplicates of requests, the Center with a larger enrollment will have the priority. After the assignments, every Center will have six months to write the first draft of the manuscript. If this is not

achieved, the Scientific Committee is entitled to assign the project to other investigators. The time line of the publications is decided by the Scientific Committee. The Center writing the draft will have the first and last name on the publication. The remaining names will be assigned based on the volume of enrollment. The first Author and the last have to be senior Authors. Before submission, every paper needs approval by all the Co Authors.”

This proposition needs to be discuss and editorial policy of the AVIATOR group needs to be clearly define.

### III. Friendly Surgical Report (Friday 18th March – 7.15 am)

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Members present: Alain Berrebi, Frederiek de Heer, Emilie Bollache, Igor Rudez, Jan Vojacek, Emmanuel Lansac, Stephanie Lejeune.

The friendly surgical report is still under development with the data provider.

The project is to have

- A general report of the hole series form the center compare to hole database at 30 mortality.
- Specific report with dynamic analysis :
  - type of surgery (valve sparing, Isolated repair, replacement)
  - Type of valve (tricuspide, bicuspide.....)
  - Phenotype of aorta (root, tubular, isolated AI)
  - Mortality
  - Reoperation
  - Residual regurgitation
  - Thrombo-embolic events
  - Bleeding
  - Endocarditis
  - Pace-Maker

All the Friendly surgical report variables will be present for each criterion above. We will be able to just select the criteria we want in order to find every parameters presents in the friendly surgical report.