



2nd steering committee meeting
MEETING MINUTES
26SEP2015
16:00 – 18:00
Mercure Hotel Amsterdam

ACTION ITEMS FOR SC MEMBERS:

1. What do we store from patients?
 - a. Blood
 - b. Lung tissue
 - c. BALF

Please send this information to Lenka Mokra (mokra@iba.muni.cz)

2. Project Proposals– The members are encouraged to propose their own projects based on the data from the registry
3. Equation for calculation of % of predicted values within the Follow up form:
 - a. Reconsider the calculation:
 - **Man:** $(FVC * 100) / ((27.63 - (0.112 * \text{age at the time of diagnosis})) * \text{height on the Enrollment form} / 1000)$
 - **Woman:** $(FVC * 100) / ((21.78 - (0.101 * \text{age at the time of diagnosis})) * \text{height on the Enrollment form} / 1000)$

If you use or suggest any other questions please send it to Lenka Mokra (mokra@iba.muni.cz)

Other information from the meeting:

1. Adverse Event form: the AE form after discussion with sponsor (BI) is in place and part of the eCRF. To have the current set up of the form was the proposal from the sponsor to follow their internal SOPs.
2. FVC: information regarding FVC are part of the Follow-up Form ONLY. Once the patient is enrolled these forms has to be created:
 - a. Enrollment form
 - b. Treatment form
 - c. Follow up – including current FVC information. Date of F-UP has to be the same as date of ICF or earlier date (validation system will be changed accordingly in upcoming dates).
3. EuroQoL – it won't be required to fill in quality of life questionnaire before the date when ICF was signed – validation system will be changed accordingly in upcoming dates
4. 6 minute walk test – won't be mandatory field anymore - validation system will be changed accordingly in upcoming dates

Next meeting will be probably held on 12th March 2016 in Prague, after CIPF meeting