

## Minutes

### YASWA Thorax registry workshop

Wednesday 8<sup>th</sup> of June 2022 - 10:00-15:00 CET

Copenhagen Airport, Clarion

**Attendees:** Ilse Duus Weinreich, Karl Lemström, Sini Puputti,, Jesper Magnusson, Sandra Lindstedt, Christian Møller, Maria W. Engmann, Michael Perch, Are Holm, Ingebjørg Kvangarsnes, Petra Vestlund

- I. **Expected benefit of this workshop:** The attendees expected a streamlining of the YASWA thoracic registry, with a simplification and reduction of parameters, and an adaptation to the requirements of the ISHLT registry and the various local registries. Some local technical solutions were discussed.
- II. **What do we have in YASWA - walk-through:** Each single sheet and tab from the YASWA thoracic registry was reviewed and adjusted. The lung registry was reviewed first, and many data points were removed or edited. After this, the heart section was reviewed. Keeping in mind that this had recently been revised, only few changes were made in the heart section.

The data points for induction therapy will be summarized by Ilse and sent to each participant for review and revision.

### III. Status from each center:

- a) Heart data entry pre tx, tx, follow up and survival\* - see above
- b) Lung data entry pre tx, tx, follow up and survival\* - see above
- c) Would you like to keep the registry in YASWA? – see pt. I and III d. It was agreed to keep the heart and lung parts of the registry separate.
- d) What would you like to use the registry for? The registry must first of all satisfy the legal requirements to enable donor and recipient traceability. Secondly, it according to EU regulations it should cover serious adverse events (SAE). Third, it should enable export of data to the ISHLT. Fourth, it should serve as a quality registry for each center. Finally, it should provide basic data for research.



**IV. What do you need in the registry? Obligatory fields for ISHLT?** See pt. II above.

**V. How do we get more people motivated to use the registry** After the point-by-point discussion of the registry contents, the discussion focused on how data entry at each center might be improved.

- a) Karl suggested an official letter from the Scandiatransplant administration to the hospital administrations at each center where the obligatory need to keep a registry would be emphasized. The purpose would be to increase local prioritization of resources to registry work.
- b) The formal responsibility of the registry was discussed. Presumably, the head of thoracic transplant at each center is also formally responsible for keeping the local portion of the registry.
- c) Status of the work with the registry will be presented at the next SHLG meeting in October

**VI. There will be a follow up workshop later this year when the updates in the registry have been done. Ilse will send out a notification when she has an overview of the completion of the tasks.**

**VII. Evaluation of the workshop**

A very productive workshop, which gave a good overview and a promising signal for the future of the registry.

**13. June 2022**

**Karl Lemström**