

Minutes from NLTR Workshop Copenhagen 21.02.2023

List of meeting participants :

Scandiatransplant, Aarhus

Ilse Duus Weinreich, Anne Boserup

Oslo University Hospital:

Espen Melum, Lise Katrine Engesæter (writer of minutes), Monika Olofsson Storrø, Martine Heggland Andresen

Tartu University Hospital

Virge Pall, Aire Rehme

Sahlgrenska University Hospital

Andreas Schult, Ulrika Samuelsson, Ulla Nyström

Copenhagen University Hospital, Rigshospitalet

Ulla Plagborg

Karolinska University Hospital

Carl Jorns, Marie Tranäng, Malin Aram

1. Presentation of participants and what would we like to get out of the workshop
2. Data entry compliance → went through NLTR data completeness on selected parameters. All over good completeness for most variables. Some are missing for several centers – due to workflow, delay in getting some of the information for instance pathology reports and because of poorly understood definitions of the variables (see below) .There are also a delay when it comes to filling out the forms. There is “quality control”- functions in YASWA → can be used to identify e.g. all patients without cause of death. All users can export data as a CSV-file → can be used for statistics. Scandiatransplant are working on a new way of producing figures and graphs directly in YASWA.
3. Finland only use limited functions in NLTR as they are awaiting automated datatransfer from their local registry. Ilse has been informed that this process is moving forward now.
4. Review of form A, B and C. How does each center handle the logistics of filling out the forms? In some centres MD`s filled out some of the/parts of the forms, and other centers used transplant/patient coordinators or a dedicated nurse for this work. Is it possible to decide on a “Best practice”/set of guidelines to how we organize this tasks?

Suggestions:

- *Digitize form A, B and C used at the hospitals*
 - *As little delay as possible*
 - *Mandatory parameters*

 - Parameters in YASWA in need of a clearer definition → Diabetes, encephalopathy, ascites, diagnoses, medical care status, Cumulative pre LTX treatment(cancer), steatosis, arterial reconstruction, early complications, kidney failure, rejection, a.hepatica thrombosis
 - Is it possible to create a solution to let patients give feedback on their QoL either via sms or a feedback form via mail? The Scandiatransplant office can not as of now offer a solution for this. This could be an issue for discussion in the Scandiatransplant board.
5. Form D; register a recipient death. Often difficult to find cause of death. Scandiatransplant is in the process of establishing automatic checking for date of death with national registries. This will help in increasing the accuracy of the registry and would reduce manual work at each center.
6. Remember to inform Scandiatransplant if there are local changes regarding biochemistry, e.g. change in units. There is already a pending issue with Alpha-1-fetoprotein, which Scandiatransplant is aware of.

Action points that were agreed upon:

1. *Pop up boxes for definitions of parameters. Suggestions to be circulated before easter to agreed upon by each center. (**Responsible:** Espen Melum / Lise Katrine Engesæter)*
2. *To be discussed at the NLTG meeting in April → It seems to be timely to do a complete revision of the current forms. Should more lab values (peth etc) be included? Do we want more about long term complications and QoL? We should be aware that making the registry to comprehensive could reduce the completeness. All changes should maintain compatibility with ELTR parameters and should be aligned with similar processes in ELTR. Establish a working group; 2 members(coordinator + MD) from each center +representatives from Scandiatransplant*
3. *Contact ELTR to investigate if any revision of the registry is planned/ongoing (**Responsible:** Ilse Duus Weinreich)*
4. *Reports that show completeness of data entry at each center will be generated. It was suggested also to include important key parameters like time on waiting list, death on waiting list etc. The goal of sending these out is for local monitoring and to generate motivation for data entry. (**Responsible:** Ilse Duus Weinreich / Anne Boserup)*