

# Minutes of the 9<sup>th</sup> ELTR Workshop

Held on Friday December 4<sup>th</sup>, 2009 (10 a.m. – 5 p.m.)

at Paul Brousse Hospital Hepatobiliary Center ,Villejuif, France.

## Participants

Fifty-one persons representing 19 countries participated to the 9<sup>th</sup> ELTR Workshop (list of participants in enclosure 1). The ELTR have received 43 registrations from 33 centres representing 19 countries, and from 3 Organ Sharing Organizations, OSOs (“Organizacion Nacional de Transplantès”, “Agence de la Biomedecine” and the Bulgarian Agency of Transplantation).

### - Participants from individual centres (32)

- Austria (1)
- Belgium (2)
- Bulgaria (2)
- Switzerland (1)
- Czech Republic (3)
- Germany (1)
- Hungary (1)
- France (3)
- UK (1)
- Italy (7)
- Norway (1)
- Poland (1)
- Romania (1)
- Slovenia (2)
- Spain (3)
- Sweden (2)

### - Organ Sharing Organizations (3)

### - ELTR auditors (3)

### - ELTR team (4)

### - New ELITA board members (9)

Program of the workshop (enclosure 2)

## Data capture and update. Quality control of ELTR data

After the welcome addresses by René Adam (RA) and Andrew Burroughs, President of the new ELITA board, Vincent Karam (VK) gave a historical recall of the evolution of ELTR questionnaire. When the initial version (1984 - 1995) contained only 14 variables, the current version contains 64 variables, 74 variables in case of living donation and additional 81 variables in case the recipient had a HCC diagnosis. The evolution of the questionnaire was necessary in order to evaluate precisely the current status of LT in Europe. The quality of the ELTR depends not only on the quality of analyzed

data but also of the standardization of the questionnaire.

In order to show the quality of each variable, VK have done a simulation of data capture and update. The rate of missing data and the most frequent errors of data capture encountered during the data control procedures were discussed with the participants.

A specific discussion concerned the MELD score and the variables required for its calculation. In some situation, the centers correct the MELD score by adding some points in case of HCC,..., according to the local rules. It was recommended that only the latest laboratory tests before LT (INR, Serum Bilirubin and Creatinine) have to be filled in.

The procedure for an adequate report of the diagnoses was also clarified, mainly in case of combined diagnoses like for HCC with cirrhosis or cirrhosis with incidental HCC. The rank (Dis1 or Dis2) according to the main disease was explained. Others issues were also discussed (report of the cause of death or graft failure, follow-up of immunosuppression treatment,...).

In order to face the fast increase of volume of data, the issue about the possibility of partial or total data's transfer from local systems to the ELTR was discussed. To this end, VK will send to the centers the ELTR database's specifications as soon as possible. The specification contains the structure of the database, name and nature of variables, and the list of codes with their definition.

In conclusion, the rate of missing data is higher for the newly added variables than for the old variables. This status can be explained by:

(1) the fact that some OSO did not yet start to fill in them,

(2) It brings additional work to the transplant coordinators and the difficulty to obtain some of them like pathology report of tumor characteristics,...

By providing centres with the database specifications, they will be able to alleviate the load of work while programming an export of data, total or partial.

## Results of the last Audit Visits

Wolfgang Wannoff, ELTR auditor, presented a report of the audit results for 47 centres that are performing LRLT. He showed that:



(1) The rate of completeness and consistency of LRLT files are similar to those of cadaveric LT. In cohorts, completeness and consistency were higher than 95.2% and 96.8%, respectively.

(2) The quality of data of the centres audited on 2008 was slightly lower than the one of centres audited on 2007

(3) Some specific living donor variables should be targeted for improvement (Min PT, Serum bilirubin, early complications and, mainly the donor outcome).

Audit visits have been suspended during 2009 because of a financial support lack. But during 2010, 5 centers will be audited. Henceforth, all the variables of the questionnaire, including the new ones, will be controlled.

**The confidential statistics of each center**

Valérie Delvart (VD), ELTR Biostatistician presented the procedure of data analysis specific to each center with comparison to overall ELTR results. She showed how to access the password protected space in the website to download the actualized slides and also how to access to the center specific data analysis.

**Review of the ELTR Studies. How to lead a study on ELTR material**

RA explained:

- How to apply for an ELTR-based study
- Regulations for ELTR-based studies and publications

Even if the number of publication continue to progress, it is still lower with consideration of the available ELTR tool. However, the ELTR has published 19 papers in the main revues (table 1).

Revue	No
The Lancet	3
Annals of Surg.	2
Am J Transplant.	1
Liver Transplantation	4
Transplantation	2
J hepatol.	2
Am J Gastroenterol.	1
Transplant International2	
Transplant Proc.	1
<b>Total</b>	<b>19</b>

Table 1

The ELTR is increasingly present to the congresses. The figure 1 shows the evolution of the ELTR participations with the name of the congresses and the number of communications.

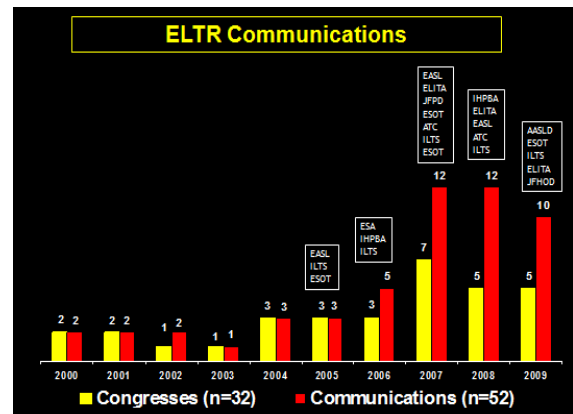


Figure 1

The evolution of 32 study projects was also presented.

Finally, we tried to evaluate the number of citations of ELTR in the literature. The use of PubMed displayed 29 citations. This number is certainly under-estimated because the research in PubMed concerns only the title and the abstract. The ELTR could have been cited in the introduction or the discussion of more other publications.

**Survey on the scientific usefulness of ELTR**

The ELTR have performed a survey to have the opinion of the participating centers. The results revealed that:

- The ELTR is often used by 71% of participants
- 81% of participants judge the ELTR as very useful (indispensable for 26%)
- 69% consider ELTR information as main
- 70% report that the ELTR is often mentioned in the congresses or in the literature
- 94% consider ELTR data as good (excellent for 31%)
- 70% think that the ELTR is really representative

Details are summarized in the enclosure 3.

Finally, the ELTR team wishes to all the participants to the registry a Happy New Year 2010.

Villejuif on January 15, 2010

