

MINUTES of meeting concerning import of kidneyTx follow-up data to SCTP

Time for the meeting: September 15, 2014 from 11:00 to 15:00

Place: The Library at department of Nephrology P 2132, Rigshospitalet, Blegdamsvej 9, Copenhagen.

Participants:

- Moderator: Søren Schwartz Sørensen (SSS), soeren.schwartz.soerensen@regionh.dk
- Representatives of National kidney registries:
 - Sweden: K.G.Pruz (KGP), KG.Pruz@med.lu.se
 - Norway: Torbjørn Leivestad (TLE), tlevest@ous-hf.no & Anders Åsberg, aaasbe@ous-hf.no
 - Denmark: James Heaf (JHE), d110582@dadlnet.dk
 - Finland: Marko Lempinen (ML), Marko.Lempinen@hus.fi
 - Iceland: Runólfur Pálsson (RPA), runolfur@landspitali.is
- Scandiatransplant (SCTP):
 - Director: Kaj Anker Jørgensen (KAJ), kaj.joergensen@skejby.rm.dk
 - Office: Ilse Duus Weinreich (IDW), ilse.duus.weinreich@scandiatransplant.org
 - Office: Frank Pedersen (FP), frank.pedersen@scandiatransplant.org
 - Office: Torben Helligsø, tgh@scandiatransplant.org
 - Office: Bo Hedemark Pedersen (BHP), bhp@scandiatransplant.org

The meeting was held according to the agenda sent to all participants in advance.

Sweden: started officially in 1991 (but data back to 1964), all involved centers reports directly to the central database. Comparison to central national registry of operations gives a 98% match. But according to dialysis-comparison there are 21 (counties) instances of registries - so this is a bit more cumbersome to compare. Validation against death-registry is done annually. sc-numbers are missing in the database.

Iceland: tx done in Göteborg/Sahlgrenska. The registry is combined tx and dialysis. The main software is Filemaker. Reporting is done to sctp and edta. sc-numbers has been added to the registry. There was a misunderstanding with the definition of onset-date. Cause of death (and date) is done "from time to time" - often when the data is needed - and not annually. No official annual report - but reported to various institutions.

Finland: Has two registries, a uremic registry and a transplantation registry, data entry e.g. graft loss must be done both places.. Helena is head of conversion to a new system - which will primarily be reflected on the tx-reg.

Norway: only one tx-center and one database - all enters into the same system, which has export-facilities for statistical work; e.g. Torbjørns Medlog-system. Actually data are extracted from two parts: the tx-info (tx-date, ischemia-time etc.) is drawn from the hospital system and the dialysis-data are collected on paper forms. Only the tx-part contains the sc-number entered by the tissue-typers. Updated against the national death-registry (though not to be trusted on diagnosis - given by the local nephrologist).

Denmark: Tx+dialysis (15 centers - 3 of the do tx). DNSL. Death-check once a year - comparison of national cause of death. SC-number not in database - but merged by the file given by sctp.

FP: cmo made the script for upload - excel-date-formatting `_does_ matter` - must be consistent within the database. You can always upload a new version, which will overwrite any previously uploaded version; e.g. if you find any errors in the previous one.

SSS: fu-date should be the last date where the registry has anything registered.

TLE: N register the FU-date when the national registry has marked a person as 'lost-to-follow-up' (e.g. emigrated). This means that the censor-date must be that date; e.g. graft life-time - important for statistics!

KGP: if no events have been registered the last date of the year should be entered.

TLE: it doesn't matter if e.g. a date of death in the year of import is uploaded, as it will just be cut to 31st of Dec. last year in survival analysis. (or 1st of Jan. - midnight anyway). date of emigration is registered in fu-date.

SSS: is the time-limit (1st of April) unrealistic?

All but Sweden: it's ok. KGP: 1st of May

IDW: were sitting next to Nina Ask (Finland) when uploading their version - which finally turned up completely successful. Comments concerning the Finish import: As of April 1st, 2014 survival status is updated on all recipients, it is not necessarily so when it comes to graft loss. Hospital and home haemodialysis is not differentiated in their registry, all has been converted to 1. Hospital haemodialysis. In the Icelandic registry there is no onset date, why this field is left empty in the import. In the end the error-list was narrowed down to 8 incidents, where two of them were due to tx in the US. Sweden had a lot of discrepancies of more than one day, which should be sorted out by the local centers - Furthermore around 40 tx. registrations from 1995-1998 are missing in SCTP, if possible these will be reconstructed. Altogether down to 104 errors still left.

SSS: walkthrough of validation. Some of the records - like no RRT-date is pointing to IS - which doesn't even have the sc# involved !?

KGP: onset-date is not mandatory.

RP: date of onset is the responsibility of the tx-center

SSS: onset-date is missing 15% of the time - which is not a problem of translation but simply because it is not in the import files. onset-date before tx-date seems like a problem of translation - not in the import files. Perhaps data are extracted that only exists in sctp.

FP: two qc's are made that are only available for the x-users:

1. Test tx exists with no follow-up at all
2. For a specified period of time return patients with no follow-up

SSS: transfer of patients between countries - at the moment lost-to-followup is noted.

TLE: it is a problem that we cannot enter fu-data on e.g. a Danish patient that is tx'ed in Oslo and then returned to dk. JHE: reconstructs the tx-entrance in order to register FU

SSS: should we have another field flagging if the person is emigrated. Emigrated: Yes/No - should be optional as Finland may have a problem supplying this value.

KGP: it seems illogical that one should put tx as RRT at tx when this is the first with no previous dialysis (pre-emptive tx). All agree that RRT should be expanded by a value 6: Pre-emptive.

RP: will get follow-up data of icelandic patients from DNSL and the database at Sahlgrenska

FP: you can download all kidney-data in sctp in the old sqlforms for your own center - just for looking at what exists.

TLE: you can instruct the system of which tx-number the patient is waiting for when adding a new entry in the sctp-waiting-list, if you need in old records you must contact Ilse or Frank

everybody agrees that it is worth the effort of importing the data.

TODO:

- check that the date-format should not matter.
- check comparison excluding data before 1995
- upload-script: check that fu-date is always the last
- TLE: import files must contain these columns - *in this order*
- *Add validation check: No dates after 'follow up date'.*
- TLE: it checks both the patient-id and the CPR- and not all patients in sctp has the last 4-5 digits.

- TLE: Date of donation? SCTP internally - should not block upload. Should be sorted out internally. Leave out the checks against donation data.
- TLE: a specific patient has tx-dates two days in a row - the graft-loss of the 1st one is on the date of the 2nd. And when data are returned it states that the 2nd graft is also lost. This situation is colliding with the margin of +- 1 day of tx-date acceptance.
- IDW: we should state, based on the import script, what are blockers and what are warnings only.
- remove the specifications of RTT-at-tx (IPD, CAPD, CCPD)

Writer of minutes: Bo Hedemark Pedersen