

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

Time for the meeting: October 17, 2012 from 10:00 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
 - Denmark: James Heaf (JHE), d110582@dadlnet.dk
 - Finland: Lauri Kyllönen (LKY), Lauri.kyllonen@fimnet.fi
 - Iceland: Runólfur Pálsson (RPA), runolfur@landspitali.is
- Scandiatransplant (SCTP):
 - Board-member: Lars Wennberg (LWE), lars.wennberg@karolinska.se
 - Office: Christian Mondrup (CMO), reccmo@scandiatransplant.org
 - Office: Bo Hedemark Pedersen (BHP), bhp@scandiatransplant.org

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

1. Welcome

SSS welcomed all participants and explained the purpose of the meeting which was triggered by inconsistencies in the data returned by SCTP (cf. 2) both in general and in relation to the individual national registry.

2. Presentation of problems encountered during analysis of the latest follow up data from SCTP

SSS reports that many follow-up-dates are shortly after the given tx-date, which makes the data worthless for survival-calculations. This seems to apply to Swedish data solely.

TLE gives examples of scandianumbers (sc#) where graft-loss occurs before tx-date and explains that it might have something to do with the fact that the SCTP accepts discrepancies of up till 2 days between tx-dates in the SCTP-registry and national registries. Anyways data in scandiatransplant should be consistent. TLE states that Norway have max 5 patients who are tx'ed twice on the same date. TLE adds (by mail 2012-10-22) until this day FU-files from Norway

does not include data on tx done elsewhere than OS; e.g. we have pt.s who are tx'ed in another nordic center and then moved to Norway: these are not included in Norwegian FU-data. TLE questions if other countries are reporting FU abt. pt.s who are tx'ed elsewhere.

CMO states that date of death should be overruled by national registries.

TLE do not export data of pts tx'ed outside of sctp.

3. Short presentation of the different Nordic registries

Finland/LKY: this reg. is independent of the Finnish kidney (dialysis) reg.; tx-number(tx#) is starting from first time tx'ed in finland (not outside e.g. Pakistan). mssql-server; browser-interface, contains waiting list, tx-date is date and time of reperfusion. Medication is logged, lab-data are imported automatically which gives a fu-date, with some single cases where patient is lost to fu; e.g. suddenly reappears in dialysis. The Finnish reg. is not compared to the national death registry automatically. One single person (secretary) is updating the database. LKY is doing the analysis. cross checks are done between the registries. sc# is only in the tx-db - not the uremia.

Iceland/RPA: originally built to report to others (EDTA), build on FileMaker operated by RPA mostly. One IT-person (started as a student) develops the reg. Updates are reported to a web-site. Data includes lab-data; which at the moment are entered retrospectively. Are updated 5-10 years (depending) by national death registry; otw entered manually. FU-date is the last report; or event like loss or death. Need data from other registries as tx are done outside of Iceland. Data are reviewed each time (e.g export to sctp) as the amount of tx is so small. SC# is not included; imported by feedback. The system is linked to national patient reg. in order to grant permission by the national data agency. Tx# is fed back from another system. Would like the national cpr returned as well in order to implement the sc#.

Sweden/KGP: renal-replacement is event-driven; i.e. no followup-date is noted unless something happens. Data goes back from 1964. Reporting to EDTA. Date of tx, date of onset, - graftloss, four tx-centers - but only two centers can access the db., tx-reg. in stockholm/upsala with more detailed, mssql-server2008, .net4.0; death-date is cross checked annually (spring) against national death-reg.; direct access is granted by authority, tx# is the actual patient tx, sc# is not in the reg.

Denmark/JHE: annually reported to authorities, onset-func.-date, acute rejection, loss, annually crosscheck against national population reg., tx# is the actual user, mssqlserver2008, .net2.0, webbased registered by local centers (secretaries, nephrologists), sc# is not part of the reg., but contained in a private mapping table. tx# can be considered the maximum value when inconsistencies occur between a national reg. and that of sctp. Morsdate needs to get imported from national death registry; some pts however still gets treated even though they're registred as immigrated.

Norway/TLE: uremia-reg. are separated from tx-reg., which contains uremia patients once they have been tx'ed. tx-reg is an Oracle-db (not sure what the frontend is - but its not web) shared with Tx-immunology lab (so HLA antibodies etc need not be entered by surgeons or other clinicians). Surgeons registers transplantation (Day 0) with a number of associated data (cold ischaemia, anastomose-details, basic immunosuppression etc). The surgeon also adds a one-week state (with such medication and creatinine and start date). Nephrologist then places a 3-months-status with fairly similar data surgeon 7-day. Events, such as rejection episodes, serious complications etc recorded separately (m date association) - by custom "profiles" - the rejection: start date, creatinine v start, max and at the end, biopsy assessments (by Banff system).

TLE extracts as the recorded data from the Oracle database to its Medlog-"copy" (having done an extensive check of data! - Medlog; will probably be faced out) - It is from this base he makes excel exclusions to Scandia-f.up. Each year exclusion is complete - ie if a kidney was reported as lost in one year, details about renal input and output also reported in the following year! Safety against duplication of sc # is probably not complete the current system - the Swedish date format can easily create confusion for us, so that someone can "force detect" as new a person that already exists in the database. How often it has occurred is not known.

Data goes back to 1963 for analysis; graft-loss and loss of life is entered, local centers report followup annually (reminded if not responding), 3-4 times/year crosscheck against national reg. for death-data; local centers are contacted to detail death-data, fu-date is the last trusted date (when checked against local centers); ie. annually, sc# is included, exports only tx still functioning kidneys, tx# is the actual number of the tx of the pt (e.g. starts with #2 if the patient was tx'ed before first tx in Norway). TLE asks if there could be a problem when a norwegian patient is moving to dk- that he/she will get a national (perhaps temporary) cpr.; and perhaps a new sc#? CMO states that the cpr# is not a key and can be changed along with the nationality thus keeping the sc#.

4. Technical aspect of import at present state

CMO explains that he runs an import script based on the imports, which up front have been through some manual revision by Frank Pedersen, SCTP-office, in order to have the same formats, thus emphasizing the need for a definition of a common import format.

5. General discussion regarding ambitions for import frequency and requirement for export files from individual registries i.e. how to optimize import

BHP: we go through the fields as outlined in the presentation:

<https://docs.google.com/presentation/edit?id=0AXPLLCOjSgSzZGt0Ym1kc18yODdobjhiaHZn>

JHE: the date type in Excel is defined as days since 1900-Jan-0 in excel (format); i.e. 1st of Jan

1900 is the number 1. This means that the date-format isn't important as long as it's typed as a date.

LKY states that the Finnish reg. and sctp has the same tx-date.

JHE suggests that national registries should have the possibility to overrule sctp-tx-dates. Everybody agrees to this happening automatically during import, when the discrepancy is at most 2 days. But when the difference is 3 days or more it should be listed as an inconsistency (as a result of the upload) and afterwards be validated and fixed manually in whatever register holds the wrong value. BHP will request the board of an approval of this procedure.

JHE suggests that sctp could keep their own tx-date in a special file.

Everybody agrees that:

- the import format should be readable by Microsoft Excel, .xls-format ([BIFF8](#) - and not Excel 2007, i.e. .xlsx), which is exportable by most systems.
- sc# should be the key-field - and national cpr left out (as well as name of the patient). TLE: sctp should send out cpr-no. and sc#pairs - everybody agrees to this and CMO responds that he will prepare the data
- TLE: tx-date should at minimum be 01-Jan-1995
- date-fu: should be filled in when this check has been performed as well as feedback from the centers (graft-loss etc.) have been performed. KGP: suggests the last date of the year. LKY states that the Finnish registry has an ambition to check regularly (annually).
- status should be deleted from export. CMO: sctp is calculating status, so it doesn't have to get imported.
- date of graft-loss: all delivers in date-type (no specific format).
- cause of graft-loss: should not be included for now; each center should figure out how to collect the data and check what format it's in and feedback to this group.
- date of death: everybody should check against other reg. (national death reg.)
- cause of death: should not be included; as it depends of how you define it
- date of onset: [corrected by SSS, 2012-10-21 to:] all delivers in date-type. There is no sctp-def. - defined by local center; e.g. SSS: date (in date-type) of last dialysis - and LKY: a def. a when and how creatinine decreases etc.
- tx-no.: should be exported; sctp-tx#. is per graft
- the feedback/export from sctp should contain two fields with tx-no. according to sctp and according to local registry.
- an upload should be responded with a list/report of inconsistencies
- JHE suggests to include date of first renal treatment (CMO: should be implemented already - and should be overwritten by renal registries) as well as dialysis-modality at time of tx., TX, HD,PD or HD/PD (could it be none?)
- SSS: acute rejection is too loose defined
- SSS: we should stick to the data above until we have something automatized and up and running.
- data should be sent in March each year - meaning the first report could be done in 2013

BHP will create a template excel-file and feedback exactly how to retrieve the sc#/cpr-lists as well as how to upload the final file exported by the national registry

6. Import of follow up data in the future - can this be done in a more elegant and time saving way

BHP: we will stick to the excel-upload for now in order to have something quick running. The technical details of each registry were requested in order to produce some auxiliary code-samples for a future exchange through the web services exposed by sctp. Finland, Sweden and Denmark should have no problems connecting to the web-services, whereas it's unclear for now if it's a possibility for Iceland and Norway.

All agrees that they would like technical details of how to communicate with the web-service interfaces with coding-stubs as examples.

7. Late breaking points to the agenda

TLE: will send specific examples of problems with mismatches in response-data

Recorder of minutes: BHP