

Manual for the ID Database

To collect the data from the Lung Transplant patients each hospital gets its own a MS-Access database (DB). This manual is written to comment on required and voluntary data entry fields to ease data entry.

You start the DB and you open in the objects "form" the form "transplant_form".

Data entry starts at the field "hospital ID". The tab key can be used to navigate from field to field in a logic way.

Data entry field	comment
Name of the hospital	Every DB sent to a participant can only use his own hospital key, other hospitals are blocked
ID-DB	Each participant hospital uses a fixed account of ID-numbers for its patients. E.g. Hannover uses numbers between $\geq 10,000$ and $< 20,000$, numbers available for each participant were provided at the first start of the DB by the DB administrator Frank Schwab
Recipient ID	Here the patient ID should be entered which is used in the respective hospital. The use this ID makes a reidentification of the patients possible for the respective hospital. The recipient ID may use parts of the name or a number or any combination of both
Year of birth	Year of birth
Date of admission	Date of the admission during which the lung transplantation was performed.
Date of transplantation	Date of transplantation
Gender	Gender
Date of discharge	Date of discharge of the hospital stay during which the transplantation was performed
Patient entry complete	Please mark this field only if all entries required for the surveillance module chosen is made. This field should be a help for you for your on-line documentation of all patients. Using this field all uncompleted patients can be displayed
Date of last observation	For those transplant groups who want to survey for a long post-transplant period the data of the last contact should be entered to get an estimate for the overall follow-up. This date can be always changed when the patients is seen again.
Race	The drop down menu allows the choice between European, Hispanic, African or unknown
Date of death	Date of death
Cause of death	Free text field, the most probable cause of death should be recorded as detailed as possible. Example: NOT: Sepsis and multiple organ failure BUT mediastinitis and secondary sepsis
Operating procedure	Use drop down menu: combined transplantation means any lung transplantation combined with another organ other than

	heart, a specification of combination is made in the field “combined or single lung specification”. If a single lung transplantation is performed specify right or left in the field “combined or single lung specification”
OP free text	This field may be used if unusual operating procedures were performed e.g. additional heart valve replacement
Volume reduction procedure	If mismatch of the volume of the transplant lungs occurs the volume may be reduced by a volume reduction procedure. If this technique is used it should be recorded here
Indication for Tx	Use drop down menu. If you choose “other” please specify in the free-text field
Redo-Tx	If a second, third or fourth organ is transplanted please specify re, re-re or re-re-re Tx
ECMO prior to Tx	If an ECMO is implanted before or post-Tx record the date of implantation
Ventilation prior to Tx	Enter the date since when the patient was ventilated prior to Tx
Number of post-Tx-ventilation periods	If the patient is once or more often reventilated post-Tx record the number of different ventilation periods.
Duration of post-Tx ventilation	Give the sum of all post-Tx ventilation days even if the ventilation period was interrupted once or several times. Give not the sum of hours divided by 24h but count each day during which a ventilation occurred.
CMV status donor	Use drop down menu. The diagnosis is made by a positive or negative serological result (CMV-specific IgG) before transplantation. Here no PCR diagnostic is required
CMV status recipient	See above but for the recipient.
CMV prophylaxis	Use drop down menu. Here only the initial posttransplant prophylactic regimen is required
Duration of CMV prophylaxis	Record the duration of the initial prophylaxis, if a CMV disease occurs during prophylaxis, record the duration until positive CMV-signs
Immunosuppression	Record the initial immunosuppression using the drop down menus
If you survey pneumonias choose “pneumonia”, if you diagnosed a pneumonia in the patient you are entering	
Type of pneumonia	Specify the type of pneumonia according to our definitions
Date of NI	Give the date of pneumonia onset (first date from either radiological signs or microbial findings or clinical findings (according to our definitions)
Pneumonia site if OP SLTX	Specify the pneumonia body site for SLTx patients
Pathogens of pneumonia	Choose up to three organisms using drop down menus
Remark to NI	This free text field may be used if pathogens or clinical signs

	were present which fit not in the other fields
Rejection	Use drop-down menu
Date of rejection	Date of rejection
Response to rejection therapy	Enter if a positive response to the therapy was observed
Remark to rejection	Free text field may be used for additional observations
If you survey invasive mycotic infection (IMI), CMV disease or urinary tract infection (UTI)/ blood stream infection (BSI)/ surgical site infection (SSI) choose appropriate "IMI", "CMV disease" or "UTI/BSI/SSI", if you diagnosed this infection/disease in the patient you are entering	
IMI	Here IMIs (invasive mycotic infection) may be recorded according to our proposed definitions. The field are defined accordingly to those for pneumonia
CMV disease	Here CMV diseases/reactivations may be recorded according to our proposed definitions. The field are defined accordingly to those for pneumonia
UTI/BSI/SSI	Here UTI (urinary tract infection)/BSI (blood stream infection) /SSI (surgical site infection) may be recorded according to our proposed definitions. The field are defined accordingly to those for pneumonia

Each participant has to sign in to get his own database which is identified by assigned numbers for patients "ID-DB". This system allows a quick merging of all DBs sent to different participants.

For the test-period the participants send the current hospital-transplant-DB to the transplant centre in Hannover. For sending the DB, the DB is encrypted and compressed (WINZIP) with a password. The password gets the participants with their DB.

Annually all participants receive descriptive statistics for the data of their own hospital and the pooled descriptive statistics of all participating hospitals.