

# User manual

## All recipients

### Recipient and waiting list administration

#### 09dec2015

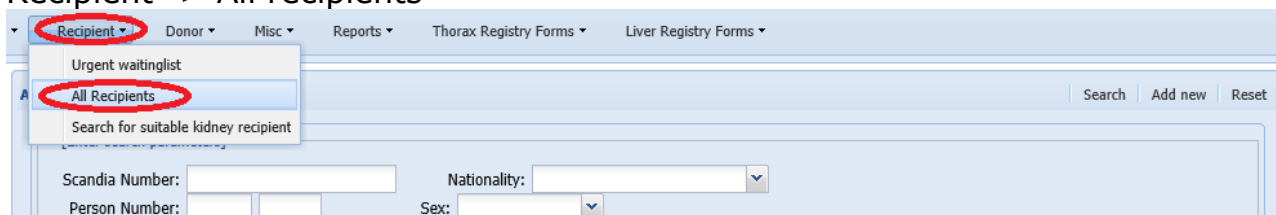
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STAMP/LAMP is described in a separate manual

#### 1. Find the menu 'All Recipients'

Recipient -> All recipients



## 2. Find an existing patient in the database

When you enter the menu 'All recipients' you get a variety of possibilities for entering search parameters. You can search on one parameter or combine more parameters to limited the number of recipients.

**All Recipients** Search Add new Reset

[Enter search parameters]

Scandia Number:  Nationality:

Person Number:  Sex:

Surname:  First Name:

Transplant Center:  AB0 Blood Group:

Waiting list status:  Waiting List type:  Urgency:

**STAMP** **Historical**

Sign up:  Status:  Termination:

Withdrawal:  Waiting List:

Scandia Num... Nationality Person Number Surname First Name Transplant Ce... AB0 Blood Gr... Waiting list st... Waiting List t... Urgency

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Example of a search based on a combination of three parameters:

**All Recipients** Search Add new Reset

[Enter search parameters]

Scandia Number:  Nationality:

Person Number:  Sex:

Surname:  First Name:

Transplant Center: CP: København AB0 Blood Group:

Waiting list status: N: Notified Waiting List type: KI: Kidney Urgency:

**STAMP** **Historical**

Sign up:  Status:  Termination:

Withdrawal:  Waiting List:

	Scandia Num...	Nationality	Person Number	Surname	First Name	Transplant Ce...	AB0 Blood Gr...	Waiting list st...	Waiting List t...	Urgency
1				Surname: M.	First name: S.	CP: København	A	N: Notified	KI: Kidney	T: Transplant...
2				Surname: N.	First name: M.	CP: København	A	N: Notified	KI: Kidney	T: Transplant...
3				Surname: S.	First name: B.	CP: København	0	N: Notified	KI: Kidney	T: Transplant...
4				Surname: D.	First name: B.	CP: København	0	N: Notified	KI: Kidney	T: Transplant...
5				Surname: D.	First name: J.	CP: København	A	N: Notified	KI: Kidney	T: Transplant...
6				Surname: B.	First name: A.	CP: København	B	N: Notified	KI: Kidney	T: Transplant...
7				Surname: R.	First name: J.	CP: København	A	N: Notified	KI: Kidney	T: Transplant...
8				Surname: P.	First name: J.	CP: København	A	N: Notified	KI: Kidney	T: Transplant...

At the bottom of the page the total number of recipients fulfilling the search parameters are displayed (No. 1).  
 Furthermore, the order of the list is displayed (No. 2), if you wish to change the order click on the column headers (No. 3).

**All Recipients** Search Add new Reset

[Enter search parameters]

Scandia Number:  Nationality:

Person Number:  Sex: F: Female

Surname:  First Name:

Transplant Center: CP: København AB0 Blood Group: 0

Waiting list status:  Waiting List type: LI: Liver Urgency:

**STAMP** **Historical**

Sign up:  Status:  Termination:

Withdrawal:  Waiting List:

3.	Scandia Num...	Nationality	Person Number	Surname	First Name	Transplant Ce...	AB0 Blood Gr...	Waiting list st...	Waiting List t...	Urgency
1					First name: J.	CP: København	0	N: Notified	LI: Liver	T: Transplant...
2					First name: E.	CP: København	0	N: Notified	LI: Liver	T: Transplant...
3					First name: K.	CP: København	0	N: Notified	LI: Liver	T: Transplant...
4					First name: B.	CP: København	0	N: Notified	LI: Liver	T: Transplant...
5					First name: E.	CP: København	0	N: Notified	LI: Liver	T: Transplant...

Page 1 of 1 2. Order by: Organization Scandia Number 1. Displaying 1 - 5 of 5

Below is an example of changed sorting, if you wish to go back to the default sorting click on the 'Order by:' button.

	Scandia Num...	Nationality	Person Number	Surname	First Name	Transplant Ce...	AB0 Blood Gr...	Waiting list st...	Waiting List t...	Urgency
1						CP: København	0	N: Notified	LI: Liver	T: Transplant...
2						CP: København	0	N: Notified	LI: Liver	T: Transplant...
3						CP: København	0	N: Notified	LI: Liver	T: Transplant...
4						CP: København	0	N: Notified	LI: Liver	T: Transplant...
5						CP: København	0	N: Notified	LI: Liver	T: Transplant...
6						CP: København	A	N: Notified	LI: Liver	T: Transplant...
7						CP: København	A	N: Notified	LI: Liver	T: Transplant...
8						CP: København	B	N: Notified	LI: Liver	T: Transplant...
9						CP: København	B		LI: Liver	

Page 1 of 1 Order by: Waiting list status AB0 Blood Group Displaying 1 - 9 of 9

Press to reset ordering to default

### 3. Register a new patient – Basic information

The screenshot shows the 'All Recipients' search interface. At the top right, there are buttons for 'Search', 'Add new' (circled in red), and 'Reset'. Below this is a search form with the following fields:

- Scandia Number:
- Nationality:
- Person Number:
- Sex:
- Surname:
- First Name:
- Transplant Center:
- AB0 Blood Group:
- Waiting List:
- Urgency:
- Notification:

Below the main search fields are two sections: 'STAMP' and 'Historical'. The 'STAMP' section includes 'Sign up', 'Withdrawal', and 'Status' dropdowns. The 'Historical' section includes 'Termination' and 'Waiting List' dropdowns.

Click on 'Add new'

The screenshot shows the 'Recipient information' form. At the top right, there are buttons for 'Back', 'Save', and 'Cancel'. The form includes the following fields:

- Scandia Number:
- Nationality:
- Date of Birth:
- Person Number:
- Sex:
- Surname:
- First Name:
- Transplantation History:
- Survival Status:
- Status:
- Waiting List:
- Urgency:
- First regist.:
- Latest regist.:

Below the form are tabs for 'Basic info', 'Clinical data', 'Address/Phone', 'Waiting List', 'HLA Typing', 'Antibody Screen Test', 'Allowable Antibodies', 'Previous Mismatches', and 'Death'. The 'Basic info' tab is active and shows the following fields:

- AB0 Blood Group:
- Rhesus:
- Transplant center:
- Department:
- Notes on Patient:

Start entering information.

Mandatory data to fill in before getting a Scandia number is; Date of birth, Sex, Surname, First name and AB0 blood group.

The person number will be validated according to the registered nationality and national rules. Furthermore, it will be checked if the patient has been registered previously in the database.

## 4. Register and/or update of patient information

### 4.1. HLA typing

Basic info	Clinical data	Address/Phone	Waiting List	HLA Typing	Antibody Screen Test	Acceptable Antibodies	Previous Mismatches	Death
Serological								
A:				B:				
CW:				BW4/w6:				
DR:				DQ:				
Genomic								
A:				B:				

Enter the HLA type or select between HLA types by pressing the drop down menu. To select a specific type on the list, click on it.

07  
0702  
0703  
0736  
08  
0801  
13  
1301  
1302  
14  
1401  
1402  
15  
1501  
1502

If you start typing, the list will narrow down

B: 1  
13  
1301  
1302  
14  
1401  
1402  
15  
1501  
1502  
1503  
1504  
1505  
1506  
1507  
1508

Bw4 and Bw6 is automatically calculated from the association to the HLA type, but **not** automatically counted as part of the patient HLA. To use the calculated Bw4 and Bw6 you have to enter them into the HLA registration fields.

The screenshot displays the 'HLA Typing' tab with the following fields:

- Serological:** A: 1, 3; B: 51, 7; Cw: ; DR: ; DQ: ; Bw4/w6: w4, [red box]
- Genomic:** A: ; B: ; DRB1: 15, 10; DPA1: ; DQA1: ; DRB3/4/5: ; DPB1: ; DQB1: ; [red box]
- For match:** A: 1, 3; B: 5, 7; Cw: ; DR: 2, 10; DQ: ;

## 4.2. Antibody Screen Test

The screenshot displays the 'Antibody Screen Test' tab with the following fields:

- Antibody Summary:** B+X,7;
- Calculated combined PRA:** 28 %
- Immunization:** PI: Previously immunized

In this tab, you are able to register new antibody results and to get an overview of the antibody status.

To add a new antibody screen test result click on 'Add new'

The screenshot displays the 'Recipient information' tab with the following fields:

- Scandia Number:** 950234
- Nationality:** DK: Denmark
- Date of Birth:** 01-Feb-1988
- Person Number:** 010288
- Sex:** F: Female
- Surname:** x
- First Name:** x
- Transplantation History:** KI; LI; PA; IT; HE; LU;
- Survival Status:** ALIVE
- Status:** ; **Waiting List:** ; **Urgency:** ;
- First regist.:** IDW, 03-Mar-2015
- Latest regist.:** IDW, 03-Mar-2015

Below the recipient information is the 'Antibody Screen Test' sub-tab with the following fields:

- Antibody Summary:** ;
- Calculated combined PRA:** %
- Immunization:** ND: Not investigated, unknown

At the bottom, there is an 'Add new' button circled in red and a table with the following columns:

Date of sample	PRA Class I	PRA Class II	Identified Antibodies
----------------	-------------	--------------	-----------------------

Fill in date, PRA and technic used

If you wish to fill in antibody specificities you can click on the arrow down and list of value will appear. Now you can click on the specificities on the list that you wish to add.

When you save and go back the newly added screen test result will appear on the list.

	Date of sample	PRA Class I	PRA Class II	Identified Antibodies
1	09-Mar-2015	15	0	B13,7,8;
2	25-May-2010	0	0	
3	20-Apr-2010	0	0	
4	20-Jan-2010	10	0	
5	05-Nov-2009	10	0	

If you wish to alter/add information to an already registered result, you click on the specific line and a pop up window will appear.

### 4.3. Acceptable antibodies

The screenshot shows a software interface with several tabs: Basic info, Clinical data, Address/Phone, Waiting List, HLA Typing, Antibody Screen Test, **Acceptable Antibodies**, Previous Mismatches, and Death. The 'Acceptable Antibodies' tab is active and highlighted with a red border. It contains a text field for 'Antibody Summary' with the value 'B+X,13,7,8;' and a dropdown menu for 'HLA-B:'.

Previously determined antibodies which are no longer clinical relevant, can be specified in this tab.

The screenshot shows a software interface with several tabs: Basic info, Clinical data, Address/Phone, Waiting List, HLA Typing, Antibody Screen Test, **Allowable Antibodies**, Previous Mismatches, and Death. The 'Allowable Antibodies' tab is active and highlighted with a purple border. Above the tabs is a 'Recipient information' section with fields for Scandia Number (950234), Nationality (DK: Denmark), Date of Birth (01-Feb-1988), Person Number (010288), Sex (F: Female), Surname (x), First Name (x), Transplantation History (KI; LI; PA; IT; HE; LU;), Survival Status (ALIVE), Status, Waiting List, Urgency, First regist. (IDW, 03-Mar-2015), and Latest regist. (IDW, 03-Mar-2015). The 'Allowable Antibodies' tab contains a text field for 'Antibody Summary' with the value 'A19,(9);' and a dropdown menu for 'HLA-A:' with a list of values: '9' and '19'. The '9' value is currently selected and highlighted.

In list of value you can chose between all antibodies determined. The antibodies that you select as no longer relevant will be displayed in brackets after saving data.



## 4.4. Previous Mismatches

Previous Mismatches				
	Series	Antigene	Acceptable mismatch	Tx. registration in SCTP
<input checked="" type="checkbox"/>	A	1	N: No	N: No
<input checked="" type="checkbox"/>	B	12	N: No	N: No

This tab contains information on HLA mismatches from previous transplantations and allows registration of missing previous mismatches.

Previous Mismatches				
	Series	Antigene	Acceptable mismatch	Tx. registration in SCTP
<input checked="" type="checkbox"/>	A	1	N: No	N: No
<input checked="" type="checkbox"/>	A	3	N: No	Y: Yes
<input checked="" type="checkbox"/>	B	37	N: No	N: No
<input checked="" type="checkbox"/>	B	40	N: No	N: No
<input type="checkbox"/>				N: No

If the previous transplantation(s) has been registered in the database and donor HLA has been filled in HLA mismatches will automatically be calculated and displayed. In the column 'Tx. Registration in SCTP' these will be listed as Yes.

If the transplantation is not registered in the database (mainly kidney transplantations before 1<sup>st</sup> of January 1995) you can register previous mismatches manually.

A previous mismatch is a default set to not acceptable, which means that it will appear on the kidney search result list as a repeated mismatch if the donor type includes the specific HLA type. If the value in the 'Acceptable mismatch' column is changed to yes, it will not appear as a repeated mismatch on the search result list.

## 5. Waiting list

### 5.1. Waiting list history

When you click on the waiting list tab you will get an overview of the waiting list history, sorted with the newest entry in top.

You can click on terminated waiting list records to view read only data or you can enter a not yet terminated record to view and/or alter data.

The screenshot shows the 'Recipient information' form with the following fields:

- Scandia Number: [ ]
- Nationality: S: Sweden
- Date of Birth: [ ]
- Person Number: [ ]
- Sex: F: Female
- Surname: [ ]
- First Name: [ ]
- Transplantation History: (0)KI; (3)LI 15-JAN-1994 29-DEC-2005 31-JAN-2011; (0)PA; IT; HE; LU;
- Survival Status: ALIVE
- Waiting list status: N: Notified
- Waiting list type: LI: Liver
- Urgency: T: Transplantable
- First regist.: OPS\$ 08-Nov-1995
- Latest regist.: OPS\$ 31-Jan-2011

The 'Waiting List' tab is selected, showing a table with the following data:

	Waiting List	Date of entry	Termination
1	LI: Liver	11-Mar-2015	
2	LI: Liver	15-Nov-2010	Transplantation - cadaveric donor <- Donor: 6389 , Tx-date: 31-JAN-11
3	LI: Liver	22-Sep-2005	Transplantation - cadaveric donor <- Donor: 3223 , Tx-date: 29-DEC-05
4	LI: Liver	11-Nov-1993	Transplantation - cadaveric donor <- Donor: 8699, Tx-date: 15-JAN-94

### 5.2. Preparation for new waiting list entry (new, previously transplanted/withdrawn)

The procedure to enroll a patient on a waiting list is the same, whether the patient has been on or never been on the waiting list before.

Enter the waiting list tab and click on 'Add new' to create a new waiting list entry.

The screenshot shows the 'Recipient information' form with the following fields:

- Scandia Number: 950231
- Nationality: DK: Denmark
- Date of Birth: 12-Dec-2012
- Person Number: 121212
- Sex: F: Female
- Surname: x
- First Name: x
- Transplantation History: KI; LI; PA; IT; HE; LU;
- Survival Status: ALIVE
- Status: [ ]
- Waiting List: [ ]
- Urgency: [ ]
- First regist.: IDW 04-Mar-2015
- Latest regist.: IDW 04-Mar-2015

The 'Waiting List' tab is selected and circled in red. Below the tabs, the 'Add new' button is also circled in red. The table below the button is empty.

	Treatment number	Waiting List	Termination
--	------------------	--------------	-------------

A new window will pop up with the possibility to enter waiting list data

Only specification of waiting list type is mandatory.  
 'Date of entry' is automatically filled in and is the date the waiting list record was created (first registration on the actual waiting list record).

### 5.3. Infection serology

Infection serology follows the specific waiting list entry, to register and update infection serology enter the specific open waiting list entry.

#### 5.4. On waiting list (active/on hold)

To activate the patient on the waiting list select an urgency status from list of value. When data is saved the recipient is on the waiting list (active/on hold).

The screenshot shows the 'Recipient treatment' form with the following data:

- Scandia Number: 188844
- Surname: Surname: H.
- Waiting list type: KI: Kidney
- Date of entry: 10-Mar-2015
- Urgency: T: Transplantable** (highlighted)
- Date of first urgency: 10-Mar-2015** (highlighted)
- Transplant center: HE: Helsinki
- Treatment center: [dropdown]
- Immunization: NI: Non immunized
- Date of last change of Immunization: 23-Dec-2014
- STAMP Sign Up: [text box]
- STAMP Status: [text box]

Below the generic data, there are tabs for 'Specific data', 'Infection serology', 'STAMP/LAMP', 'STAMP QC', 'Urgency History', and 'Termination'. The 'Kidney Waitinglist' section includes fields for 'Waiting For Kidney Number' (2), 'Local Urgency Code' (dropdown), 'Special Preferences' (dropdown), 'Other special requirements' (text box), 'Dialysis at entry' (dropdown), and 'Start of dialysis' (calendar icon).

'Date of first urgency' is the date when the recipient entered the waiting list.

#### 5.5. Change status on waiting list

If you need to change the recipient status on the waiting list enter the waiting list tab and click on the open waiting list entry

The screenshot shows the 'Waiting List' tab with the following table:

Waiting List	Date of entry	Termination
→ KI: Kidney	23-Jul-2015	

A red arrow points to the 'KI: Kidney' entry.

Select another urgency from the list. If 'Withdrawn until' is selected on a kidney patient, please insert date of active on waiting list in the 'until' field.

The screenshot shows the 'Waiting list information' form with the following data:

- Scandia Number: 19
- Surname: Surname: [dropdown]
- Waiting list type: KI: Kidney
- Date of entry: 23-Jul-2015
- Urgency: WU: Temporarily x** (highlighted)
- Until: [empty]** (highlighted)
- Date of first urgency: [dropdown menu showing options: NT: Temporarily not transplantable, T: Transplantable]
- Transplant center: WU: Temporarily withdrawn until specified date
- Immunization: NI: Non immunized
- Date of last change of Immunization: 17-Aug-2015
- STAMP Sign Up: [text box]
- STAMP Status: [text box]

## 5.6. Withdrawal from waiting list

To withdraw a recipient from the waiting list, select the tab Termination, followed by a 'Termination cause'.

The screenshot shows the 'Recipient treatment' form with the 'Termination' tab selected. The 'Termination Cause' dropdown is highlighted with a red box and a red arrow pointing to it. The dropdown menu is open, showing three options: 'CDT: Transplantation - cadaveric donor', 'LDT: Transplantation - living donor', and 'PW: Permanent withdrawal for other reason'.

### An example of a permanent withdrawal

The screenshot shows the 'Recipient treatment' form with the 'Termination' tab selected. The 'Termination Cause' dropdown is set to 'PW: Permanent withdrawal for other reason' and the 'Termination Date' is '10-Mar-2015'. Below this, the 'Recipient Withdrawn' section shows the 'Withdrawal Cause' dropdown set to 'CI: Improved condition' and the 'Withdrawal Date' is '01-Mar-2015'.

If you withdraw a recipient as living or deceased donor transplanted a shortcut to the transplantation registration will appear in the bottom. Click on the line and you will be transferred to the transplantation registration screen.

The screenshot shows the 'Recipient treatment' form with the 'Termination' tab selected. The 'Termination Cause' dropdown is set to 'CDT: Transplantation - deceased donor' and the 'Termination Date' is '04-Sep-2015'. Below this, a table titled 'Transplantation (deceased donor)' is shown. The table has columns for 'Organ type', 'Donor number', 'Person number', 'Donor name', 'Country', 'Procuring center', 'Tx. center', and 'Date of transplanta...'. The first row shows 'KI: Kidney' with a red arrow pointing to it.

If the recipient has died on the waiting list, withdrawal from the waiting list is done when death registration is done as described in the next section.

## 6. Death registration

To death register a recipient, whom is off/on/on hold from the waiting list, chose the tab 'Death' and fill in the information.

Recipient information Back Save Cancel

Scandia Number:  Nationality: N: Norway

Date of Birth:  Person Number:  Sex: F: Female

Surname:

First Name:

Transplantation History: (0)KI; LI; PA; IT; HE; LU;

Survival Status: DEAD 03-MAR-2015 after waiting list termination

Waiting list status:  Waiting list type: KI: Kidney  Urgency:

First regist.: OPSI  09-Mar-2015  Latest regist.: IDW  10-Mar-2015

**Basic info** Clinical data Address/Phone Waiting List HLA Typing Antibody Screen Test Acceptable Antibodies Previous Mismatches **Death**

Recipient Death

Treatment number:  Treatment type: KI

Cause of Death: 14: Other causes of cardiac failure  Status: T: Dead after waiting list termination

Date of Death: 03-Mar-2015