



## WP 4 'LIVING DONOR REGISTRIES'

# DATA SET AND DATA DICTIONARY

NATIONAL REGISTRY

AND

SUPRANATIONAL REGISTRY OF REGISTRIES

(including glossary of terms)



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## 1. NATIONAL REGISTRY: KIDNEY

### 1.1 DONOR DEMOGRAPHIC INFORMATION

Nr.	Item	Definition	Units	M/O <sup>1</sup>
1	Identification (ID number, initials)	The unique identification code that is given by the national authorities to each person, or a possibility to collect initials.		M
2	Date of birth		DD/MM/YYYY	O
3	Age	Actual age at the time of donation	years, no decimals	M
4	Gender		Male/Female	M
5	Weight		kg, no decimals	M
6	Height		cm, no decimals	M
7	Blood group	Menu: - A - B - 0 - AB	Choosing one from this menu	M
8	Address		Open field	O
9	Country of residence		ISO code 3166	M
10	Nationality		ISO code 3166	M
11	Ethnicity	Menu: - White - Asian - Black - Oriental - Mixed, please specify - Other, please specify	Choosing one or multiple from this menu and free text field for 'specify:.....'	O

### 1.2 PRE-DONATION DATA

Nr.	Item	Definition	Units	M/O <sup>2</sup>
1	Relation type	A living donor has one of the following three possible relationships with the recipient <sup>3</sup> : - A/ Related - A1/ Genetically related: a. 1 <sup>st</sup> degree genetic relative: parent, sibling, offspring b. 2 <sup>nd</sup> degree genetic relative: e.g. grandparent, grandchild, aunt, uncle, niece, nephew, c. Other than 1 <sup>st</sup> or 2 <sup>nd</sup> degree	Choosing one from this menu	M

<sup>1</sup> M = Mandatory, O= Optional

<sup>2</sup> M = Mandatory, O= Optional

<sup>3</sup> WHO, Global glossary of terms and definitions on Donation and Transplantation

		<p>genetic related, for example cousin</p> <ul style="list-style-type: none"> <li>- A2/ Emotionally related: Spouse (if not genetically related); in-laws; adopted, friend</li> <li>- B/ Unrelated: non-related = not genetically or emotionally related.</li> </ul>		
2	Blood pressure	Actual blood pressure (independent of the method of measurement)	mmHg	O
3	Hypertension		Yes / No	O
4	Antihypertensive treatment	<p>Menu:</p> <ul style="list-style-type: none"> <li>- Nothing</li> <li>- Diet only</li> <li>- Medication: <ul style="list-style-type: none"> <li>- Diuretics</li> <li>- Beta blockers</li> <li>- ACE blockers</li> <li>- A2 antagonists</li> <li>- Vasodilators/Calcium channel blockers</li> <li>- Other</li> </ul> </li> <li>-</li> </ul>	Choosing one or multiple items from this menu	M
5	Creatinine		Umol/L or mg/dl	M
6	Proteinuria	PCR (protein creatinine ratio)	mg/mmol creat	M
7	Any significant co-morbidity	<p>Menu:</p> <ul style="list-style-type: none"> <li>- No</li> <li>- Yes, specify: <ul style="list-style-type: none"> <li>- Abdominal surgery, specify...</li> <li>- Malignancies, specify...</li> <li>- Hematological disease, specify...</li> <li>- Neurological disease, specify...</li> <li>- Cardiovascular disease, specify...</li> <li>- Respiratory disease, specify...</li> <li>- Gastrointestinal disease, specify...</li> <li>- Psychiatric disease, specify...</li> <li>- Psychological disorder, specify...</li> <li>- Renal / urinary tract disease, specify...</li> <li>- Other, specify...</li> </ul> </li> <li>- Unknown</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify:.....'	M

### 1.3 PERI- AND POST-OPERATIVE DATA (until discharge)

Nr.	Item	Definition	Units	M/O <sup>4</sup>
1	Donor hospital (center) name	List to be built by countries.		M
2	Country of donor hospital	The country in which the donation takes place	ISO code 3166	M

<sup>4</sup> M = Mandatory, O= Optional

3	Date of donation		DD/MM/YYYY	M
4	Left or right kidney		Left / Right	M
5	Operation technique	Menu: <ul style="list-style-type: none"> <li>- Open technique <ul style="list-style-type: none"> <li>a. Classic technique <ul style="list-style-type: none"> <li>- Costal resection</li> <li>- No costal resection</li> </ul> </li> <li>b. Mini-incision</li> </ul> </li> <li>- Laparoscopic <ul style="list-style-type: none"> <li>a. Standard</li> <li>b. Hand assisted laparoscopic</li> </ul> </li> <li>- Other, specify...</li> </ul>	Choosing one from this menu	M
6	Complications during operation	Menu: <ul style="list-style-type: none"> <li>- No complications</li> <li>- Blood loss: need for transfusion</li> <li>- Kidney damaged during retrieval <ul style="list-style-type: none"> <li>a. Kidney can be used for transplantation</li> <li>b. Kidney is discarded for transplantation</li> </ul> </li> <li>- Other organ damaged during surgery</li> <li>- Switch from laparoscopic procedure to open technique</li> <li>- Cardiac arrest</li> <li>- Other severe complications (i.e. pneumothorax, anaphylactic reaction) (specify...)</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify...'	M
7	Complications after operation – until first discharge	Menu: <ul style="list-style-type: none"> <li>- No complications</li> <li>- Blood loss: need for transfusion</li> <li>- Need for re-operation</li> <li>- Infection (urinary, wound, other)</li> <li>- Thrombo/embolic complications (DVT, pulmonary embolism)</li> <li>- Renal Replacement Therapy, specify...</li> <li>- Cardiac arrest</li> <li>- Other severe complications (specify...)</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify...'	M
8	Length of hospital stay (LOS)	The number of days in hospital during the first admission (from day of surgery until discharge)	Number of days	O
9	Number of days in ICU	The number of days in Intensive Care Unit during the first admission (until discharge)	Number of days	O

#### 1.4 FOLLOW-UP DATA

Nr.	Item	Definition	Units	M/O <sup>5</sup>
1	Follow-up center	List to be built by countries.		M
2	Date of follow-up		DD/MM/YYYY	M
3	Donor lost to follow-up		Yes / No	M

<sup>5</sup> M = Mandatory, O= Optional

4	Death		Yes / No	M
5	Cause of death	All coding systems are allowed		M
6	Date of death		DD/MM/YYYY	M
7	Weight		kg, no decimals	M
8	Blood pressure	Actual blood pressure (independent of the method of measurement)	mmHg	O
9	Hypertension		Yes / No	O
10	Antihypertensive treatment	Menu: <ul style="list-style-type: none"> <li>- Nothing</li> <li>- Diet only</li> <li>- Medication: <ul style="list-style-type: none"> <li>- Diuretics</li> <li>- Beta blockers</li> <li>- ACE blockers</li> <li>- A2 antagonists</li> <li>- Vasodilators/Calcium channel blockers</li> <li>- Other</li> </ul> </li> </ul>	Choosing one or multiple items from this menu	M
11	Creatinine		Umol/L or mg/dl	M
12	Proteinuria	PCR (protein creatinine ratio)	mg/mmol creat	M
13	Health issues	Menu: <ul style="list-style-type: none"> <li>- No</li> <li>- Yes, specify: <ul style="list-style-type: none"> <li>- Abdominal surgery, specify...</li> <li>- Malignancies, specify...</li> <li>- Hematological disease, specify...</li> <li>- Neurological disease, specify...</li> <li>- Cardiovascular disease, specify...</li> <li>- Respiratory disease, specify...</li> <li>- Gastrointestinal disease, specify...</li> <li>- Psychiatric disease, specify...</li> <li>- Psychological disorder, specify...</li> <li>- Renal / urinary tract disease, specify...</li> <li>- Renal Replacement Therapy, specify...</li> <li>- Pregnancy, specify (when)....</li> <li>- Diabetes mellitus, specify...</li> <li>- Other, specify...</li> <li>- Unknown</li> </ul> </li> </ul>	Choosing one or multiple from this menu and free text field for 'specify:.....'	M
14	Did the donor return to previous activity level?  (This item should only be collected during the 12 month follow-up visit.)	Menu: <ul style="list-style-type: none"> <li>- Yes, within .... months</li> <li>- No</li> <li>- Unknown</li> </ul>	Choosing one from this menu and free text field for ' ... months'	O

## 2. REGISTRY OF REGISTRIES: KIDNEY

### 2.1 DONOR DEMOGRAPHIC INFORMATION

Nr.	Item	Definition	Units	M/O <sup>6</sup>
1	Identification (ID number, initials)	The unique identification code that is given by the national authorities to each person, or a possibility to collect initials.		M
2	Date of birth		DD/MM/YYYY	O
3	Age	Actual age at the time of donation	years, no decimals	M
4	Gender		Male/Female	M
5	Weight		kg, no decimals	M
6	Height		cm, no decimals	M
7	Blood group	Menu: - A - B - O - AB	Choosing one from this menu	M
8	Country of residence		ISO code 3166	M
9	Nationality		ISO code 3166	M
10	Ethnicity	Menu: - White - Asian - Black - Oriental - Mixed, please specify - Other, please specify	Choosing one or multiple from this menu and free text field for 'specify:.....	O

### 2.2 PRE-DONATION DATA

Nr.	Item	Definition	Units	M/O <sup>7</sup>
1	Relation type	Menu: - Related a. Genetically b. Non-genetically - Unrelated	Choosing one from this menu	M
2	Antihypertensive treatment	Menu: - Nothing - Diet only - Medication: - Diuretics - Beta blockers - ACE blockers - A2 antagonists	Choosing one from this menu	M

<sup>6</sup> M = Mandatory, O= Optional

<sup>7</sup> M = Mandatory, O= Optional



		<ul style="list-style-type: none"> <li>- Vasodilators/Calcium channel blockers</li> <li>- Other</li> </ul>		
3	Creatinine		Umol/L or mg/dl	M
4	Proteinuria	PCR (protein creatinine ratio)	mg/mmol creat	M
5	Any significant co-morbidity	Menu: <ul style="list-style-type: none"> <li>- No</li> <li>- Yes, specify:               <ul style="list-style-type: none"> <li>- Abdominal surgery, specify...</li> <li>- Malignancies, specify...</li> <li>- Hematological disease, specify...</li> <li>- Neurological disease, specify...</li> <li>- Cardiovasculair disease, specify...</li> <li>- Respiratory disease, specify...</li> <li>- Gastrointestinal disease, specify...</li> <li>- Psychiatric disease, specify...</li> <li>- Psychological disorder, specify...</li> <li>- Renal / urinary tract disease, specify...</li> <li>- Other, specify...</li> </ul> </li> <li>- Unknown</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify:.....'	M

### 2.3 PERI- AND POST-OPERATIVE DATA (until discharge)

Nr.	Item	Definition	Units	M/O <sup>8</sup>
1	Country of donor hospital	The country in which the donation takes place	ISO code 3166	M
2	Date of donation		DD/MM/YYYY	M
3	Left or right kidney		Left / Right	M
4	Operation technique	Menu: <ul style="list-style-type: none"> <li>- Open technique               <ul style="list-style-type: none"> <li>a. Classic technique                   <ul style="list-style-type: none"> <li>- Costal resection</li> <li>- No costal resection</li> </ul> </li> <li>b. Mini-incision</li> </ul> </li> <li>- Laparoscopic               <ul style="list-style-type: none"> <li>a. Standard</li> <li>b. Hand assisted laparoscopic</li> </ul> </li> <li>- Other, specify...</li> </ul>	Choosing one from this menu	M
5	Complications during operation	Menu: <ul style="list-style-type: none"> <li>- No complications</li> <li>- Blood loss: need for transfusion</li> <li>- Kidney damaged during retrieval               <ul style="list-style-type: none"> <li>a. Kidney can be used for transplantation</li> <li>b. Kidney is discarded for transplantation</li> </ul> </li> <li>- Other organ damaged during surgery</li> <li>- Switch from laparoscopic procedure</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify...'	M

<sup>8</sup> M = Mandatory, O= Optional

		<p>to open technique</p> <ul style="list-style-type: none"> <li>- Cardiac arrest</li> <li>- Other severe complications (i.e. pneumothorax, anaphylactic reaction) ( specify...)</li> </ul>		
6	Complications after operation – until first discharge	<p>Menu:</p> <ul style="list-style-type: none"> <li>- No complications</li> <li>- Blood loss: need for transfusion</li> <li>- Need for re-operation</li> <li>- Infection (urinary, wound, other)</li> <li>- Thrombo/embolic complications (DVT, pulmonary embolism)</li> <li>- Renal Replacement Therapy, specify...</li> <li>- Cardiac arrest</li> <li>- Other severe complications (specify...)</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify...'	M
7	Length of hospital stay (LOS)	The number of days in hospital during the first admission (from day of surgery until discharge)	Number of days	O
8	Number of days in ICU	The number of days in Intensive Care Unit during the first admission (until discharge)	Number of days	O

## 2.4 FOLLOW-UP DATA

Nr.	Item	Definition	Units	M/O <sup>9</sup>
1	Date of follow-up		DD/MM/YYYY	M
2	Donor lost to follow-up		Yes / No	M
3	Death		Yes / No	M
4	Cause of death	All coding systems are allowed		M
5	Date of death		DD/MM/YYYY	M
6	Weight		kg, no decimals	M
7	Antihypertensive treatment	<p>Menu:</p> <ul style="list-style-type: none"> <li>- Nothing</li> <li>- Diet only</li> <li>- Medication: <ul style="list-style-type: none"> <li>- Diuretics</li> <li>- Beta blockers</li> <li>- ACE blockers</li> <li>- A2 antagonists</li> <li>- Vasodilators/Calcium channel blockers</li> <li>- Other</li> </ul> </li> </ul>	Choosing one from this menu	M
8	Creatinine		Umol/L or mg/dl	M
9	Proteinuria	PCR (protein creatinine ratio)	mg/mmol creat	M
10	Health issues	<p>Menu:</p> <ul style="list-style-type: none"> <li>- No</li> <li>- Yes, specify:</li> </ul>	Choosing one or multiple from this menu and free	M

<sup>9</sup> M = Mandatory, O = Optional

		<ul style="list-style-type: none"> <li>- Abdominal surgery, specify...</li> <li>- Malignancies, specify...</li> <li>- Hematological disease, specify...</li> <li>- Neurological disease, specify...</li> <li>- Cardiovascular disease, specify...</li> <li>- Respiratory disease, specify...</li> <li>- Gastrointestinal disease, specify...</li> <li>- Psychiatric disease, specify...</li> <li>- Psychological disorder, specify...</li> <li>- Renal / urinary tract disease, specify...</li> <li>- Renal Replacement Therapy, specify...</li> <li>- Pregnancy, specify (when)....</li> <li>- Diabetes mellitus, specify...</li> <li>- Other, specify...</li> <li>- Unknown</li> </ul>	text field for 'specify:.....'	
11	<p>Did the donor return to previous activity level?</p> <p>(This item should only be collected during the 12 month follow-up visit.)</p>	<p>Menu:</p> <ul style="list-style-type: none"> <li>- Yes, within .... months</li> <li>- No</li> <li>- Unknown</li> </ul>	Choosing one from this menu and free text field for ' ... months'	○

### 3. NATIONAL REGISTRY: LIVER

#### 3.1 DONOR DEMOGRAPHIC INFORMATION

Nr.	Item	Definition	Units	M/O <sup>10</sup>
1	Identification (ID number, initials)	The unique identification code that is given by the national authorities to each person, or a possibility to collect initials.		M
2	Date of birth		DD/MM/YYYY	O
3	Age	Actual age at the time of donation	years, no decimals	M
4	Gender		Male/Female	M
5	Weight		kg, no decimals	M
6	Height		cm, no decimals	M
7	Blood group	Menu: - A - B - 0 - AB	Choosing one from this menu	M
8	Address		Open field	O
9	Country of residence		ISO code 3166	M
10	Nationality		ISO code 3166	M
11	Ethnicity	Menu: - White - Asian - Black - Oriental - Mixed, please specify - Other, please specify	Choosing one or multiple from this menu and free text field for 'specify:.....'	O

#### 3.2 PRE-DONATION DATA

Nr.	Item	Definition	Units	M/O <sup>11</sup>
1	Relation type	A living donor has one of the following three possible relationships with the recipient <sup>12</sup> : - A/ Related - A1/ Genetically related: a. 1 <sup>st</sup> degree genetic relative: parent, sibling, offspring b. 2 <sup>nd</sup> degree genetic relative: e.g. grandparent, grandchild, aunt, uncle, niece, nephew, c. Other than 1 <sup>st</sup> or 2 <sup>nd</sup> degree	Choosing one from this menu	M

<sup>10</sup> M = Mandatory, O= Optional

<sup>11</sup> M = Mandatory, O= Optional

<sup>12</sup> WHO, Global glossary of terms and definitions on Donation and Transplantation

		<p>genetic related, for example cousin</p> <ul style="list-style-type: none"> <li>- A2/ Emotionally related: Spouse (if not genetically related); in-laws; adopted, friend</li> <li>- B/ Unrelated: non-related = not genetically or emotionally related.</li> </ul>		
2	Any significant co-morbidity	<p>Menu:</p> <ul style="list-style-type: none"> <li>- No</li> <li>- Yes, specify: <ul style="list-style-type: none"> <li>- Abdominal surgery, specify...</li> <li>- Malignancies, specify...</li> <li>- Hematological disease, specify...</li> <li>- Neurological disease, specify...</li> <li>- Cardiovascular disease, specify...</li> <li>- Respiratory disease, specify...</li> <li>- Gastrointestinal disease, specify...</li> <li>- Psychiatric disease, specify...</li> <li>- Psychological disorder, specify...</li> <li>- Other, specify...</li> </ul> </li> <li>- Unknown</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify:.....'	M

### 3.3 PERI- AND POST-OPERATIVE DATA (until discharge)

Nr.	Item	Definition	Units	M/O <sup>13</sup>
1	Donor hospital (center) name	List to be built by countries.		M
2	Country of donor hospital	The country in which the donation takes place	ISO code 3166	M
3	Date of donation		DD/MM/YYYY	M
4	Segment donated	<ul style="list-style-type: none"> <li>- 2</li> <li>- 3</li> <li>- 2-3</li> <li>- 2-3-4</li> <li>- 5-6-7-8</li> </ul>	Choosing one from this menu	M
5	Percentage of remnant donor liver	<p>Menu:</p> <ul style="list-style-type: none"> <li>- &lt;30%</li> <li>- 30-40%</li> <li>- 41-50%</li> <li>- 51-60%</li> <li>- &gt;60%</li> </ul>	Choosing one from this menu	M
6	Complications during operation	<p>Menu:</p> <ul style="list-style-type: none"> <li>- No complications</li> <li>- Blood loss: need for transfusion</li> <li>- Liver graft damaged during retrieval <ul style="list-style-type: none"> <li>a. Liver can be used for transplantation</li> <li>b. Liver is discarded for transplantation</li> </ul> </li> <li>- Remaining liver damaged during surgery</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify...'	M

<sup>13</sup> M = Mandatory, O= Optional

		<ul style="list-style-type: none"> <li>- Other organ damaged during surgery</li> <li>- Cardiac arrest</li> <li>- Other severe complications, specify...</li> </ul>		
7	Complications after operation – until first discharge	<p>Menu:</p> <ul style="list-style-type: none"> <li>- No complications</li> <li>- Blood loss: need for transfusion</li> <li>- Need for re-operation</li> <li>- Biliary fistula</li> <li>- Biliary stenosis</li> <li>- Infection (wound, other)</li> <li>- Non-infected collection</li> <li>- Thrombo/embolic complications (DVT, pulmonary embolism, arterial thrombosis, portal thrombosis)</li> <li>- Cardiac arrest</li> <li>- Liver insufficiency</li> <li>- Other severe complications (specify...)</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify...'	M
8	Length of hospital stay (LOS)	The number of days in hospital during the first admission (from day of surgery until discharge)	Number of days	O
9	Number of days in ICU	The number of days in Intensive Care Unit during the first admission (until discharge)	Number of days	O

### 3.4 FOLLOW-UP DATA

Nr.	Item	Definition	Units	M/O <sup>14</sup>
1	Follow-up center	List to be built by countries.		M
2	Date of follow-up		DD/MM/YYYY	M
3	Donor lost to follow-up		Yes / No	M
4	Death		Yes / No	M
5	Cause of death	All coding systems are allowed		M
6	Date of death		DD/MM/YYYY	M
7	Weight		kg, no decimals	M
8	Maximum bilirubin (within 15 days after surgery)		Umol/L	M
9	Maximum INR (within 15 days after surgery)		%	M
10	AST (at 15 days after surgery)		U/L	M
11	ALT (at 15 days after surgery)		U/L	M
12	GGT (at 15 days after)		U/L	M

<sup>14</sup> M = Mandatory, O= Optional

	surgery)			
13	Platelets (at 15 days after surgery)		10*9/L	M
14	Complications (within the first 12 months)	Menu: <ul style="list-style-type: none"> <li>- Nothing</li> <li>- Thrombo/embolic complications (DVT, pulmonary embolism, arterial thrombosis, portal thrombosis, lung embolism)</li> <li>- Infection (wound, surgical site infection, infected collection, other)</li> <li>- Non-infected collection</li> <li>- Biliary stricture</li> <li>- Biliary fistula</li> <li>- Liver insufficiency</li> <li>- Hemorrhage</li> <li>- Pleural effusion</li> <li>- Other complications, specify</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify:.....	M
15	Readmission (within the first 12 months)	Menu: <ul style="list-style-type: none"> <li>- Yes, length of hospital stay</li> <li>- No</li> <li>- Unknown</li> </ul>	Choosing one and length of admission in days	M
16	Health issues	Menu: <ul style="list-style-type: none"> <li>- No</li> <li>- Yes, specify <ul style="list-style-type: none"> <li>- Abdominal surgery, specify...</li> <li>- Malignancies, specify...</li> <li>- Hematological disease, specify...</li> <li>- Neurological disease, specify...</li> <li>- Cardiovascular disease, specify...</li> <li>- Respiratory disease, specify...</li> <li>- Gastrointestinal disease, specify...</li> <li>- Psychiatric disease, specify...</li> <li>- Psychological disorder, specify...</li> <li>- Pregnancy, specify (when)....</li> <li>- Diabetes mellitus, specify...</li> <li>- Liver disease, specify...</li> <li>- Other, specify...</li> </ul> </li> <li>- Unknown</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify:.....	M
17	Did the donor return to previous activity level?  (This item should only be collected during the 12 month follow-up visit.)	Menu: <ul style="list-style-type: none"> <li>- Yes, within .... months</li> <li>- No</li> <li>- Unknown</li> </ul>	Choosing one from this menu and free text field for ' ... months'	O

## 4. REGISTRY OF REGISTRIES: LIVER

### 4.1 DONOR DEMOGRAPHIC INFORMATION

Nr.	Item	Definition	UUnits	M/O <sup>15</sup>
1	Identification (ID number, initials)	The unique identification code that is given by the national authorities to each person, or a possibility to collect initials.		M
2	Date of birth		DD/MM/YYYY	O
3	Age	Actual age at the time of donation	years, no decimals	M
4	Gender		Male/Female	M
5	Weight		kg, no decimals	M
6	Height		cm, no decimals	M
7	Blood group	Menu: - A - B - O - AB	Choosing one from this menu	M
8	Address		Open field	O
9	Country of residence		ISO code 3166	M
10	Nationality		ISO code 3166	M
11	Ethnicity	Menu: - White - Asian - Black - Oriental - Mixed, please specify - Other, please specify	Choosing one or multiple from this menu and free text field for 'specify:.....'	O

### 4.2 PRE-DONATION DATA

Nr.	Item	Definition	Units	M/O <sup>16</sup>
1	Relation type	Menu: - Related a. Genetically b. Non-genetically - Unrelated	Choosing one from this menu	M
2	Any significant co-morbidity	Menu: - No - Yes, specify: - Abdominal surgery, specify... - Malignancies, specify... - Hematological disease,	Choosing one or multiple from this menu and free text field for	M

<sup>15</sup> M = Mandatory, O= Optional

<sup>16</sup> M = Mandatory, O= Optional



		specify... - Neurological disease, specify... - Cardiovascular disease, specify... - Respiratory disease, specify... - Gastrointestinal disease, specify... - Psychiatric disease, specify... - Psychological disorder, specify... - Other, specify... - Unknown	'specify:.....	
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### 4.3 PERI- AND POST-OPERATIVE DATA (until discharge)

Nr.	Item	Definition	Units	M/O <sup>17</sup>
1	Country of donor hospital	The country in which the donation takes place	ISO code 3166	M
2	Date of donation		DD/MM/YYYY	M
3	Segment donated	<ul style="list-style-type: none"> <li>- 2</li> <li>- 3</li> <li>- 2-3</li> <li>- 2-3-4</li> <li>- 5-6-7-8</li> </ul>	Choosing one from this menu	M
4	Percentage of remnant donor liver	Menu: <ul style="list-style-type: none"> <li>- &lt;30%</li> <li>- 30-40%</li> <li>- 41-50%</li> <li>- 51-60%</li> <li>- &gt;60%</li> </ul>	Choosing one from this menu	M
5	Complications during operation	Menu: <ul style="list-style-type: none"> <li>- No complications</li> <li>- Blood loss: need for transfusion</li> <li>- Liver graft damaged during retrieval               <ul style="list-style-type: none"> <li>a. Liver can be used for transplantation</li> <li>b. Liver is discarded for transplantation</li> </ul> </li> <li>- Remaining liver damaged during surgery</li> <li>- Other organ damaged during surgery</li> <li>- Cardiac arrest</li> <li>- Other severe complications, specify...</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify...'	M
6	Complications after operation – until first discharge	Menu: <ul style="list-style-type: none"> <li>- No complications</li> <li>- Blood loss: need for transfusion</li> <li>- Need for re-operation</li> <li>- Biliary fistula</li> <li>- Biliary stenosis</li> <li>- Infection (wound, other)</li> <li>- Non-infected collection</li> <li>- Thrombo/embolic complications (DVT, pulmonary embolism, arterial thrombosis, portal thrombosis)</li> <li>- Cardiac arrest</li> <li>- Liver insufficiency</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify...'	M

<sup>17</sup> M = Mandatory, O= Optional

		- Other severe complications (specify...)		
7	Length of hospital stay (LOS)	The number of days in hospital during the first admission (from day of surgery until discharge)	Number of days	O
8	Number of days in ICU	The number of days in Intensive Care Unit during the first admission (until discharge)	Number of days	O

#### 4.4 FOLLOW-UP DATA

Nr.	Item	Definition	Units	M/O <sup>18</sup>
1	Date of follow-up		DD/MM/YYYY	M
2	Donor lost to follow-up		Yes / No	M
3	Death		Yes / No	M
4	Cause of death	All coding systems are allowed		M
5	Date of death		DD/MM/YYYY	M
6	Weight		kg, no decimals	M
7	Maximum bilirubin (within 15 days after surgery)		Umol/L	M
8	Maximum INR (within 15 days after surgery)		%	M
9	AST (at 15 days after surgery)		U/L	M
10	ALT (at 15 days after surgery)		U/L	M
11	GGT (at 15 days after surgery)		U/L	M
12	Platelets (at 15 days after surgery)		10 <sup>9</sup> /L	M
13	Complications (within the first 12 months)	Menu: <ul style="list-style-type: none"> <li>- Nothing</li> <li>- Thrombo/embolic complications (DVT, pulmonary embolism, arterial thrombosis, portal thrombosis, lung embolism)</li> <li>- Infection (wound, surgical site infection, infected collection, other)</li> <li>- Non-infected collection</li> <li>- Biliary stricture</li> <li>- Biliary fistula</li> <li>- Liver insufficiency</li> <li>- Hemorrhage</li> <li>- Pleural effusion</li> </ul>	Choosing one or multiple from this menu and free text field for 'specify:.....'	M

<sup>18</sup> M = Mandatory, O = Optional

		- Other complications, specify		
14	Readmission (within the first 12 months)	Menu: - Yes, length of hospital stay - No - Unknown	Choosing one and length of admission in days	M
15	Health issues	Menu: - No - Yes, specify - Abdominal surgery, specify... - Malignancies, specify... - Hematological disease, specify... - Neurological disease, specify... - Cardiovascular disease, specify... - Respiratory disease, specify... - Gastrointestinal disease, specify... - Psychiatric disease, specify... - Psychological disorder, specify... - Pregnancy, specify (when)... - Diabetes mellitus, specify... - Liver disease, specify... - Other, specify... - Unknown	Choosing one or multiple from this menu and free text field for 'specify:.....'	M
16	Did the donor return to previous activity level?  (This item should only be collected during the 12 month follow-up visit.)	Menu: - Yes, within .... months - No - Unknown	Choosing one from this menu and free text field for ' ... months'	O

## 5. GLOSSARY OF TERMS

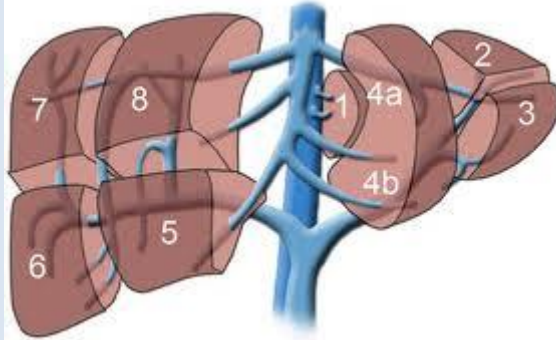
Not every item needs specification in this Glossary of terms. Some items however need an extra explanation about the way the item should be measured or collected. Another important issue is the way the registration in a national database will be translated into the supranational Registry of registries.

Item	Definition
Antihypertensive treatment	<ul style="list-style-type: none"> <li>- Nothing: this means a donor does not use any diet and/or drugs</li> <li>- Diet only: diet is not specified. Anything a person calls a diet and is appropriate to control the person's blood pressure is considered a diet.</li> </ul> <p>Medication: The following classes of antihypertensive drugs can be identified:</p> <ul style="list-style-type: none"> <li>- Diuretics</li> <li>- Beta blockers</li> <li>- ACE blockers</li> <li>- A2 antagonists</li> <li>- Vasodilators/Calcium channel blockers</li> <li>- Other</li> </ul> <p>It is assumed that every patient with a class of antihypertensive drugs has had diet advice before the treatment with medication started.</p>
Any significant co-morbidity (KIDNEY)	<p>Menu:</p> <ul style="list-style-type: none"> <li>- No</li> <li>- Yes, specify: <ul style="list-style-type: none"> <li>- Abdominal surgery, specify...</li> <li>- Malignancies, specify...</li> <li>- Hematological disease, specify...</li> <li>- Neurological disease, specify...</li> <li>- Cardiovascular disease, specify...</li> <li>- Respiratory disease, specify...</li> <li>- Gastrointestinal disease, specify...</li> <li>- Psychiatric disease, specify...</li> <li>- Psychological disorder, specify...</li> <li>- Renal / urinary tract disease, specify...</li> <li>- Other, specify...</li> </ul> </li> <li>- Unknown</li> </ul>
Any significant co-morbidity (LIVER)	<p>Menu:</p> <ul style="list-style-type: none"> <li>- No</li> <li>- Yes, specify: <ul style="list-style-type: none"> <li>- Abdominal surgery, specify...</li> <li>- Malignancies, specify...</li> <li>- Hematological disease, specify...</li> <li>- Neurological disease, specify...</li> <li>- Cardiovascular disease, specify...</li> <li>- Respiratory disease, specify...</li> <li>- Gastrointestinal disease, specify...</li> <li>- Psychiatric disease, specify...</li> <li>- Psychological disorder, specify...</li> <li>- Other, specify...</li> </ul> </li> <li>- Unknown</li> </ul>
Blood pressure	Actual blood pressure (independent of the method of measurement): the method to collect the actual blood pressure is not defined.
Cause of death	All coding systems are allowed
Complications during	Complications during operation means from the start of the surgery until

<p>operation  (KIDNEY)</p>	<p>arrival at the recovery room.</p> <p>Menu:</p> <ul style="list-style-type: none"> <li>- No complications</li> <li>- Blood loss: need for transfusion</li> <li>- Kidney damaged during retrieval: this means that the kidney that is procured from the donor (graft) is damaged <ul style="list-style-type: none"> <li>a. Kidney can be used for transplantation</li> <li>b. Kidney is discarded for transplantation</li> </ul> </li> <li>- Other organ damaged during surgery: this means another organ (not the procured organ) is (physically) damaged during the operation.</li> <li>- Switch from laparoscopic procedure to open technique</li> <li>- Cardiac arrest</li> <li>- Other severe complications (i.e. pneumothorax, anaphylactic reaction), specify...: this will be a free text field.</li> </ul>
<p>Complications during operation  (LIVER)</p>	<p>Menu:</p> <ul style="list-style-type: none"> <li>- No complications</li> <li>- Blood loss: need for transfusion</li> <li>- Liver graft damaged during retrieval: this means that the liver graft that is procured from the donor is damaged <ul style="list-style-type: none"> <li>a. Liver can be used for transplantation</li> <li>b. Liver is discarded for transplantation</li> </ul> </li> <li>- Remaining liver damaged during surgery</li> <li>- Other organ damaged during surgery</li> <li>- Cardiac arrest</li> <li>- Other severe complications, specify...</li> </ul>
<p>Complications after operation – until first discharge  (KIDNEY)</p>	<p>Complications after operation means from the departure from the recovery room until discharge from the hospital.</p> <p>Menu:</p> <ul style="list-style-type: none"> <li>- No complications</li> <li>- Blood loss: need for transfusion</li> <li>- Need for re-operation, specify...</li> <li>- Infection (urinary, wound, other): therapeutic use of antibiotics</li> <li>- Thrombo/embolic complications (DVT, pulmonary embolism)</li> <li>- Renal Replacement Therapy, specify...</li> <li>- Cardiac arrest</li> <li>- Other severe complications (specify...): this will be a free text field.</li> </ul>
<p>Complications after operation – until first discharge  (LIVER)</p>	<p>Menu:</p> <ul style="list-style-type: none"> <li>- No complications</li> <li>- Blood loss: need for transfusion</li> <li>- Need for re-operation, specify...</li> <li>- Biliary fistula: when bilirubin concentration in drained fluids is 3 or more times higher than in serum</li> <li>- Biliary stenosis</li> <li>- Infection (wound, other)</li> <li>- Non-infected collection</li> <li>- Thrombo/embolic complications (DVT, pulmonary embolism, arterial thrombosis, portal thrombosis)</li> <li>- Cardiac arrest</li> <li>- Liver insufficiency</li> <li>- Other severe complications (specify...)</li> </ul>
<p>Complications (within the first 12 months)</p>	<p>Menu:</p> <ul style="list-style-type: none"> <li>- Nothing</li> <li>- Thrombo/embolic complications (DVT, pulmonary embolism, arterial thrombosis, portal thrombosis, lung embolism)</li> <li>- Infection (wound, surgical site infection, infected collection, other)</li> <li>- Non-infected collection</li> <li>- Biliary stricture</li> <li>- Biliary fistula</li> <li>- Liver insufficiency</li> <li>- Hemorrhage</li> </ul>

	<ul style="list-style-type: none"> <li>- Pleural effusion</li> <li>- Other complications, specify</li> </ul>
Country of residence	This is the country where the person lives during 7 months of a year.
Did the donor return to previous activity level?	<p>This item should only be collected during the 12 month follow-up visit. This should be based on the person's answer and should not be an objective measurement.</p> <p>Menu:</p> <ul style="list-style-type: none"> <li>- Yes, within .... months</li> <li>- No</li> <li>- Unknown</li> </ul>
Donor lost to follow-up	A donor is lost to follow-up if he/she has regularly been invited to follow-up appointments, but did not show up during 10 years. Because the mandatory follow-up frequency is at discharge, 1 year after donation and then every 5 years, this means the donor did not show up during at least three visits.
Ethnicity	<p>Menu:</p> <ul style="list-style-type: none"> <li>- White</li> <li>- Asian</li> <li>- Black</li> <li>- Oriental</li> <li>- Mixed, please specify</li> <li>- Other, please specify</li> </ul>
Health issues (KIDNEY)	<p>Menu:</p> <ul style="list-style-type: none"> <li>- No</li> <li>- Yes, specify <ul style="list-style-type: none"> <li>- Abdominal surgery, specify...</li> <li>- Malignancies, specify...</li> <li>- Hematological disease, specify...</li> <li>- Neurological disease, specify...</li> <li>- Cardiovascular disease, specify...</li> <li>- Respiratory disease, specify...</li> <li>- Gastrointestinal disease, specify...</li> <li>- Psychiatric disease, specify...</li> <li>- Psychological disorder, specify</li> <li>- Renal / urinary tract disease, specify</li> <li>- Renal Replacement Therapy</li> <li>- Pregnancy, specify (when)....</li> <li>- Diabetes mellitus, specify...</li> <li>- Other, specify...</li> </ul> </li> </ul>
Health issues (LIVER)	<p>Menu:</p> <ul style="list-style-type: none"> <li>- No</li> <li>- Yes, specify <ul style="list-style-type: none"> <li>- Abdominal surgery, specify...</li> <li>- Malignancies, specify...</li> <li>- Hematological disease, specify...</li> <li>- Neurological disease, specify...</li> <li>- Cardiovasculair disease, specify...</li> <li>- Respiratory disease, specify...</li> <li>- Gastrointestinal disease, specify...</li> <li>- Psychiatric disease, specify...</li> <li>- Psychological disorder, specify</li> <li>- Pregnancy, specify (when)....</li> <li>- Diabetes mellitus, specify...</li> <li>- Liver disease, specify...</li> <li>- Other, specify...</li> </ul> </li> <li>- Unknown</li> </ul>
Hypertension	<p>Hypertension: Yes / No</p> <p>Hypertension should be considered 'yes' when a person uses a diet or</p>

	medication to treat the hypertension. If a person does not use a diet or medication, but has a blood pressure >140/90 mmHg, the person is also considered hypertensive.														
Identification	The national authorities in (almost) every MS give an unique identification code to each individual. This code could be used to identify a person without collecting their name. If a country decides not to use the unique identification code, another method should be used to prevent collecting data about the same person twice. For example a combination of initials and date of birth.														
Length of hospital stay (LOS)	The number of days in hospital during the first admission from day 0 to the day of discharge, with day 0 being the day of surgery.														
Nationality	In case of a double nationality, register both.														
Number of days in ICU	The number of days in Intensive Care Unit during the first admission (until discharge)														
Percentage of remnant donor liver	Menu: - <30% - 30-40% - 41-50% - 51-60% - >60%														
Readmission (within the first 12 months)	Menu: - Yes, length of hospital stay (in days) - No - Unknown														
Relation type	<p>The definition that is applicable for the national kidney database differs from the definition of the Registry of registries. To be able to collect the information, the national and supranational registries should be able to communicate with each other. The possibilities from the national database should correspond with the simplified definition:</p> <table border="1"> <thead> <tr> <th>National:</th> <th>Supranational</th> </tr> </thead> <tbody> <tr> <td>- A/ Related</td> <td>➔ Related</td> </tr> <tr> <td>- A1/ Genetically related: a. 1st degree genetic relative: parent, sibling, offspring</td> <td>➔ Genetically related ➔ Genetically related</td> </tr> <tr> <td>b. 2nd degree genetic relative: e.g. grandparent, grandchild, aunt, uncle, niece, nephew,</td> <td>➔ Genetically related</td> </tr> <tr> <td>c. Other than 1st or 2nd degree genetically related, for example cousin</td> <td>➔ Genetically related</td> </tr> <tr> <td>- A2/ Emotionally related: Spouse (if not genetically related); in-laws; adopted, friend</td> <td>➔ Non-genetically related</td> </tr> <tr> <td>- B/ Unrelated: non-related = not genetically or emotionally related.</td> <td>➔ Non-related: this means donor and recipient do not know each other</td> </tr> </tbody> </table>	National:	Supranational	- A/ Related	➔ Related	- A1/ Genetically related: a. 1st degree genetic relative: parent, sibling, offspring	➔ Genetically related ➔ Genetically related	b. 2nd degree genetic relative: e.g. grandparent, grandchild, aunt, uncle, niece, nephew,	➔ Genetically related	c. Other than 1st or 2nd degree genetically related, for example cousin	➔ Genetically related	- A2/ Emotionally related: Spouse (if not genetically related); in-laws; adopted, friend	➔ Non-genetically related	- B/ Unrelated: non-related = not genetically or emotionally related.	➔ Non-related: this means donor and recipient do not know each other
National:	Supranational														
- A/ Related	➔ Related														
- A1/ Genetically related: a. 1st degree genetic relative: parent, sibling, offspring	➔ Genetically related ➔ Genetically related														
b. 2nd degree genetic relative: e.g. grandparent, grandchild, aunt, uncle, niece, nephew,	➔ Genetically related														
c. Other than 1st or 2nd degree genetically related, for example cousin	➔ Genetically related														
- A2/ Emotionally related: Spouse (if not genetically related); in-laws; adopted, friend	➔ Non-genetically related														
- B/ Unrelated: non-related = not genetically or emotionally related.	➔ Non-related: this means donor and recipient do not know each other														
Segment donated	The liver could be divided into 8 different segments.														



The part of the liver (segment) that is procured from the donor should be specified:

- 2
- 3
- 2-3
- 2-3-4
- 5-6-7-8