

## Guidelines

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<b><u>NATIONAL REGISTRY OF DISEASES</u></b> <b><u>Single Kidney-Post Nephrectomy (Donor)</u></b> <b><u>Registration Guidelines</u></b>	<b>Document No:</b>	NRDO-G001.06b
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## ABBREVIATIONS

<b>CKD5</b>	Chronic Kidney Disease Stage 5
<b>GFR</b>	Glomerular Filtration Rate
<b>eGFR</b>	Estimated Glomerular Filtration Rate
<b>RRT</b>	Renal Replacement Therapy (e.g. Haemodialysis, Peritoneal dialysis, Renal Transplant)
<b>DCR</b>	Donor Care Registry
<b>sFTP</b>	secured File Transfer Protocol (Secured way for electronic data transmission)
<b>PGP</b>	Pretty Good Privacy (Software for encrypting data in emails)
<b>NRD</b>	National Registry of Diseases
<b>NRDO</b>	National Registry of Diseases Office

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## **Part I. INTRODUCTION**

Ministry of Health (MOH) has established the Donor Care Registry (DCR) under the National Registry of Diseases (NRD) Act to monitor living donor outcomes and post donation complications. Under the NRD Act, the manager of healthcare institution is required to report information on single kidney-post nephrectomy (donor) to the National Registry of Diseases Office (NRDO).

For the purposes of section 6(1) of the NRD Act, it is mandatory for the manager of a healthcare institution to notify the Donor Care Registry at the NRDO of the following:

- a) A person who has undergone nephrectomy for the purpose of transplantation into the body of another living person
- or
- b) The person is on undergoing treatment for single kidney – post nephrectomy (donor) at the healthcare institution (first of such treatments received by the donor at the healthcare institution on or after 1<sup>st</sup> November 2009).

The Advisory Committee on Transplant (ACT) has recommended follow-up treatment for single kidney- post nephrectomy (donor) at 4-6-weeks after nephrectomy, and then annually.

These guidelines are written to assist managers of healthcare institutions and medical practitioners to better understand the responsibilities in providing notifications of cases of Single Kidney- Post Nephrectomy (donor).

## **Part II. DEFINITION**

- “nephrectomy” - means the surgical removal of a kidney;
- “single kidney - post nephrectomy (donor)” refers to the absence of a kidney in a person, due to having undergone nephrectomy for the purpose of transplantation of his kidney into the body of another living person;
- “patient” - means a person to whom a notification referred to in regulation 3 in the National Registry of Diseases (Single Kidney-Post Nephrectomy (Donor) Notification) Regulations 2009 relates (i.e. the donor);
- “recipient” - means the person into whose body a patient’s kidney is or will be transplanted;

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### Part III. PATHWAYS AND TIMELINE FOR NOTIFICATION OF CASES

Table 1 shows the pathways and timeline for reporting cases. It is important to send listings and notifications of reportable cases not later than the timeline as stated so that NRDO can produce accurate and timely trend reports.

Managers of healthcare institutions are required to notify the cases through submission of hard or electronic copies of the notification forms / listings, within 3 months post nephrectomy and upon commencement of follow-up treatment at any healthcare institution.

**TABLE 1: Pathways and Timeline of reporting**

<b>a) REPORTING OF NEW CASE OF KIDNEY DONATION</b>		
<b>Pathways of Notification</b>	<b>Timeline</b>	<b>Mode of data transmission</b>
<p>For all kidney transplantation cases reported to NOTU - there is no need to further notify NRDO of new cases:</p> <p><b>Donor case listing -</b> will be submitted by the National Organ Transplant unit (NOTU) to NRDO to fulfill the requirements for healthcare institutions to report new cases under the NRD Act.</p>	Routine monthly reports from NOTU	sFTP

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<b>a) REPORTING OF NEW CASE OF KIDNEY DONATION</b>		
<b>Pathways of Notification</b>	<b>Timeline</b>	<b>Mode of data transmission</b>
<p>For New cases of Kidney transplantation <u>not</u> reported to NOTU:</p> <p><b>Form to use: New Case Registration Form for Kidney Donor</b></p>	<p>Within 3 months from date of nephrectomy for organ donation.</p>	<p>(1) E- Notification @ the Health Professional Portal (<a href="http://www.hpp.moh.gov.sg">www.hpp.moh.gov.sg</a>) (This is an on-line notification system for doctors to notify reportable diseases/conditions)</p> <p>Or</p> <p>(2) Hard copy can be downloaded from Registry's Internet website @ <a href="http://www.nrdo.gov.sg">http://www.nrdo.gov.sg</a> or requested from the National Registry of Diseases Office (NRDO)</p> <p>and then sent by Registered mail or by hand (including courier service) to: Donor Care Registry at the NRDO</p> <p><b>N.B. Please DO NOT submit the form via email or fax.</b></p>
<b>b) REPORTING OF TREATMENT OR FOLLOW-UP OF DONOR</b>		
<b>Pathways of Notification</b>	<b>Timeline</b>	<b>Mode of data transmission</b>
<p>For Donor undergoing treatment post nephrectomy (first of such treatment on or after 1<sup>st</sup> November 2009) at the healthcare institution:</p> <p><b>Form to use: Yearly Follow-up Form for Kidney Donor</b></p>	<p>Within 3 months after the treatment commenced at the healthcare institution e.g.</p> <ul style="list-style-type: none"> <li>• Private specialist clinic,</li> <li>• Specialist outpatient clinic at Restructured Hospitals</li> </ul>	<p>Same as above (as for notification of New cases of Kidney Donor)</p> <p><b>N.B. Please DO NOT submit the form via email or fax.</b></p>

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<b>Pathways of Notification</b>	<b>Timeline</b>	<b>Mode of data transmission</b>
For donors who are admitted to Restructured hospitals for inpatient treatment subsequent to nephrectomy  <b>Hospital Inpatient Discharge summaries listing</b>	Within 3 months after hospitalisation	(1) sFTP or PGP or encrypted electronic storage device e.g. thumb drive, CD rom.  or  (2) Hardcopy listing - by Registered mail or by hand (including courier service) to: Donor Care Registry at NRDO

**Minimal mandatory data items as listed in First Schedule of National Registry of Diseases (Single Kidney-Post Nephrectomy (Donor) Notification) Regulations 2009**

**For notification of new transplant cases or follow-up treatment at any healthcare institution, it is mandatory to furnish the following data items:**

1. Identification Number (NRIC/ Passport No/ Foreign Identification No / Hospital Registration No.)
2. Name
3. Date of Birth or age (if date of birth is unknown)
4. Name of notifying healthcare institution (including department)
5. Date of Nephrectomy (for new cases)

**Collection of additional information under section 7(1) of NRD Act**

Upon receipt of the notification, NRDO may require the manager of the healthcare institution to provide additional information. A registry coordinator from NRDO will contact the manager or the designated staff at the healthcare institution to make arrangement for visit at the healthcare institution to collect the additional information.

Alternatively, the manager of the healthcare institution may wish to furnish the additional information to NRDO via:

- a) E-Notification @ [www.hpp.moh.gov.sg](http://www.hpp.moh.gov.sg)
- or
- b) by completing the following forms (hardcopy):
  - i) New Case – New Case Registration form for Kidney Donor
  - ii) Follow-Up treatment – Yearly Follow-Up treatment form

- Note: Hardcopy form must be delivered to NRDO via Registered mail or hand delivered

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### **Yearly Follow-Up Treatment**

DCR will collect updates of the follow-up treatment (post nephrectomy) of the donor at year-end, commencing in the month of December. Healthcare institutions can work with the registry to establish the electronic transfer of data via secure file transfer protocols. Alternatively, the registry coordinators will visit the healthcare institutions or clinics for data collection.

**The manager of the healthcare institution is legally responsible to ensure that the required information is provided to the registry.**



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#### Part IV. DATA ITEMS ON NEW CASE REGISTRATION FORM FOR KIDNEY DONOR (NEW CASE)

The following table provides definitions for the data items on the New Case Registration form for kidney donor:

<b>Section 1: Particulars of Donor</b>	
<b>Data items</b>	<b>Definition</b>
Name	Record the patient's name (underline surname) from NRIC/ Passport/employment pass/work permit /Birth certificate/case-notes.
NRIC	NRIC No. } – Applicable to Singapore citizens and Permanent Residents Singapore NRIC should be entered as in the format SXXXXXXXXC or TXXXXXXXXC for those Singaporean born from 2000.
Passport No	Passport No. – Applicable to Foreigners only Enter passport no. if FIN no. is unavailable. Passport numbers enter as appears in the passport.
Foreign Identification (FIN) No.	FIN No. – Applicable to Foreigners only Enter FIN No. if patient has both FIN & Passport
Hospital Registration No.	Hospital Registration No.– Applicable to Foreigners and residents without NRIC
Date of Birth	Format is DD/MM/YYYY If only the year of birth is available then the date format will be 01/01/YYYY.
Resident Status	Tick accordingly: 1- Singapore citizen 2- Singapore Permanent Resident 3 – Others (refers to foreigners with other types of visa), select the appropriate country from the 'drop down' list (E notification).
Gender	Tick accordingly: Male or Female
Country of Birth	Patient's country of birth 1. Singapore 2. Malaysia 3. China 4. Indonesia 5. India 6. Others, specify: _____ 7. Unknown

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<b>Part IV. Data Items on New Case Registration Form for Kidney Donor (New Case)</b>	
<b>Section 1: Particulars of Donor</b>	
<b>Data items</b>	<b>Definition</b>
Ethnic Group	<p>Tick - <b>Chinese</b> / Malay / Indian / Eurasian /Others</p> <ul style="list-style-type: none"> <li>• <b>Malay</b> – refers to persons of Malay or Indonesian origin. E.g.: Boyanese, Bugis, Javanese.</li> <li>• <b>Indian</b> – Include people from India and India subcontinent. E.g.: Bangladeshi, Bengali, Malayalee, Punjabi, Sikhs, Singhalese, Sri Lankans and Tamil.</li> <li>• <b>Eurasian</b> – refers to mixed ancestry</li> <li>• <b>Others</b> – refers to groups not classified above. E.g.: Arab, Caucasian, Japanese, etc. Please specify or select from drop-down list (E notification).</li> </ul>
Marital Status	<p>Tick accordingly:</p> <ol style="list-style-type: none"> <li>1. Single</li> <li>2. Married</li> <li>3. Widowed</li> <li>4. Separated</li> <li>5. Divorced</li> <li>6. Unknown (information is unavailable)</li> </ol>
Educational Level (Highest)	<p>For those born between 1920s and 1940s, can code as: 'No Formal' or 'Low Primary' if information on education is unavailable.</p> <p>Tick accordingly:</p> <ul style="list-style-type: none"> <li>No Formal Education</li> <li>Low Primary</li> <li>PSLE (certificate)</li> <li>Secondary (No 'O' level certificate)</li> <li>GCE-N Level passes</li> <li>GCE-O Level passes</li> <li>GCE-A Level passes</li> <li>Diploma</li> <li>University &amp; above</li> <li>Not Available</li> </ul>

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<b>Section 1: Particulars of Donor</b>	
<b>Data items</b>	<b>Definition</b>
Employment status	Tick accordingly: Working full time, specify _____ Working part-time, specify _____ Not Working Retired Housewife Student Unknown (information is unavailable)
Relationship to Recipient	Tick accordingly:  A. Biologically related Parent Sibling Offspring Identical twin Others, please specify _____  B. Emotionally related Spouse Friend Others, please specify _____  C. Others Directed (Donor knows who is the recipient) Non- Directed (Donor does not know the recipient) Others, please specify _____

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<b>Part IV. Data Items on New Case Registration Form for Kidney Donor (New Case)</b>	
<b>Section 2: Particulars of Recipient</b>	
<b>Data items</b>	<b>Definition</b>
Name	Record the patient's name (underline surname) from NRIC/ Passport/employment pass/work permit /Birth certificate/case-notes.
NRIC	NRIC No. } – Applicable to Singapore citizens and Permanent Residents Singapore NRIC should be entered as in the format SXXXXXXXXC or TXXXXXXXXC for those Singaporean born from 2000.
Passport No	Passport No. – Applicable to Foreigners only Enter passport no. if FIN no. is unavailable. Passport numbers enter as appears in the passport.
Foreign Identification (FIN) No.	FIN No. – Applicable to Foreigners only Enter FIN No. if patient has both FIN & Passport
Hospital Registration No.	Hospital Registration No.– Applicable to Foreigners and residents without NRIC
Date of Birth	Format is DD/MM/YYYY If only the year of birth is available then the date format will be 01/01/YYYY.
Resident Status	Tick accordingly:  1- Singapore citizen  2- Singapore Permanent Resident  3- Malaysia  4- Indonesia  5 – Others (refers to foreigners with other types of visa), please specify or select the appropriate country from the 'drop down' list ( E notification).
Gender	Tick accordingly: Male or Female

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**Part IV. Data Items on New Case Registration Form for Kidney Donor (New Case)**

**Section 2: Particulars of Recipient**

<b>Data items</b>	<b>Definition</b>
Ethnic Group	<p>Tick - <b>Chinese</b> / Malay / Indian / Eurasian /Others</p> <ul style="list-style-type: none"> <li>• <b>Malay</b> – refers to persons of Malay or Indonesian origin. E.g.: Boyanese, Bugis, Javanese.</li> <li>• <b>Indian</b> – Include people from India and India subcontinent. E.g.: Bangladeshi, Bengali, Malayalee, Punjabi, Sikhs, Singhalese, Sri Lankans and Tamil.</li> <li>• <b>Eurasian</b> – refers to mixed ancestry</li> <li>• <b>Others</b> – refers to groups not classified above. E.g.: Arab, Caucasian, Japanese, etc. Please specify or select from drop-down list (E notification).</li> </ul>
Marital Status	<p>Tick accordingly:</p> <ol style="list-style-type: none"> <li>1. Single</li> <li>2. Married</li> <li>3. Widowed</li> <li>4. Separated</li> <li>5. Divorced</li> <li>6. Unknown (information is unavailable)</li> </ol>
Name of Recipient's Healthcare Institution	<p>Place where transplantation was performed :</p> <p><b>Tick accordingly:</b></p> <p>Singapore General Hospital  National University Hospital  Gleneagles Hospital  Mount Elizabeth Hospital  Raffles Hospital  Others, specify _____</p>

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<b>Part IV. Data Items on New Case Registration Form for Kidney Donor (New Case)</b>	
<b>Section 3: Donor Baseline Information (Pre - Donation)</b>	
<b>Data items</b>	<b>Definition</b>
Date of Baseline information	Date format DD/MM/YYYY Date of latest consultation prior to Nephrectomy.
Blood Pressure	Record systolic and diastolic blood pressure measurement in mmHg taken on the latest consultation prior to Nephrectomy.  Tick - unknown if information is unavailable.
Weight	Record the latest measurement taken and date prior to Nephrectomy  Date format DD/MM/YYYY Tick - unknown if information is unavailable.
Height	Record the latest measurement taken and date prior to Nephrectomy.  Date format DD/MM/YYYY Tick - unknown if information is unavailable.
Smoking status	Based on status nearest to the time of nephrectomy. Tick accordingly: 1. Current Smoker 2. Ex-Smoker 3. Never 4. Unknown (information is unavailable)
EQ 5D (EuroQol 5 dimensional format for health status)	Enter status of the following (on the EQ 5D form): - <ul style="list-style-type: none"> <li>• Mobility</li> <li>• Self-Care</li> <li>• Usual Activities</li> <li>• Pain/Discomfort</li> <li>• Anxiety Depression</li> </ul> Tick - unknown if information is unavailable.

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<b>Section 3: Donor Baseline Information (Pre - Donation)</b>	
<b>Data items</b>	<b>Definition</b>
Diabetes Mellitus	Tick: Yes or No or Unknown (Information is unavailable)
Oral Glucose Tolerance Test	Enter the date (DD/MM/YYYY) of test. and all results (mmol/L or mg/dl) as follow : Fasting 60 mins 120 mins Tick - unknown if information is unavailable.
Hyperlipidemia	Based on Dr's documentation nearest to the date prior to nephrectomy, tick accordingly: <ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Unknown (Information is unavailable).</li> </ul> Tick accordingly based on the results of : <ul style="list-style-type: none"> <li>• LDL cholesterol    <input type="checkbox"/> Normal    <input type="checkbox"/> Elevated</li> <li>• Triglyceride        <input type="checkbox"/> Normal    <input type="checkbox"/> Elevated</li> </ul> Tick - unknown if information (on blood test) is unavailable  Enter the date (DD/MM/YYYY) of test.
Urine FEME	Record the measurement ( _ / hpf or _ / ul) of : RBC WBC  Enter the date (DD/MM/YYYY) of test. Tick - unknown if information is unavailable.
Serum Creatinine	Enter the value in umol or mg/dl  Enter the date (DD/MM/YYYY) of test.  If Serum Creatinine is measured with IDMS standard, tick <input checked="" type="checkbox"/>  Tick - unknown if information is unavailable.

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<b>Section 3: Donor Baseline Information (Pre - Donation)</b>	
<b>Data items</b>	<b>Definition</b>
Creatinine Clearance or Radionuclide GFR	Enter the value in ml/min or ml/min 1.73m <sup>2</sup>  Enter the date (DD/MM/YYYY) of test.  Tick - unknown if information is unavailable.
24 Hr Urine protein	Record the measurement in _g/day or mg/day <sup>#</sup>  Enter the date (DD/MM/YYYY) of test.  Tick - unknown if information is unavailable.
Anti-Hypertensive medication	Tick: Yes / No / Unknown  If Yes, enter number of drugs donor is taking
Hypolipidemic drugs	Tick: Yes / No / Unknown  If Yes, enter number of drugs donor is taking
Other Abnormalities of Kidney	From x-ray / imaging reports (e.g. CT scan, MRI) Tick accordingly: <input type="checkbox"/> Stone ( Indicate Right or Left or Both Kidneys) <sup>#</sup> <input type="checkbox"/> Cyst (Indicate Right or Left or Both Kidneys) <sup>#</sup> <input type="checkbox"/> Other abnormalities specify condition: _____  (Indicate Right or Left or Both kidneys) <sup>#</sup>  Enter the date (DD/MM/YYYY) of test  Tick - unknown if information is unavailable.

# delete where applicable



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<b>Section 4: Data Related to Donor Nephrectomy</b>	
<b>Data items</b>	<b>Definition</b>
Date of Nephrectomy	Enter the date (DD/MM/YYYY)
Place of Surgery	Tick accordingly:  Singapore General Hospital National University Hospital Gleneagles Hospital Mount Elizabeth Hospital Raffles Hospital Others, specify _____
Name of Lead surgeon	Enter name of Surgeon in-charge
Type of Nephrectomy	Tick one of the following method: <ul style="list-style-type: none"> <li>• Hand-Assisted Laparoscopic Donor Nephrectomy</li> <li>• Laparoscopic</li> <li>• Conversion from Laparoscopic to open</li> <li>• Open</li> </ul>
Complications during hospitalisation	<ul style="list-style-type: none"> <li>• Tick NO if there is nil complication</li> <li>• Tick accordingly for Renal Failure/Impairment: <ul style="list-style-type: none"> <li>○ No</li> <li>○ If Yes, enter the date of Renal failure/impairment (DD/MM/YYYY)</li> </ul> </li> </ul> Or For other conditions - Surgical / Medical / Others: specify the condition
Date of initial discharge	Enter the date (DD/MM/YYYY) of discharge
Live donor discharge disposition (status)	Tick either: Alive or Dead
<b>Section 5: Details of notifying healthcare institution</b>	
Name of notifying healthcare institution (including department)	Name of Hospital / clinic / transplant centre which made the notification
Name of notifying Person	Name of Doctor / Nurse who made the notification
Date of notification	Enter the date (DD/MM/YYYY)

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**Part V. DATA ITEMS ON YEARLY FOLLOW-UP FORM FOR KIDNEY DONOR**

The following table provides definitions for the data items on the Yearly Follow-up form collected annually.

<b>Section 1. Particulars of donor (at follow-up)</b>	
<b>Data items</b>	<b>Definition</b>
Name	Record the patient's name (underline surname) from NRIC/ Passport/employment pass/work permit /Birth certificate/case-notes.
NRIC	NRIC No. } – Applicable to Singapore citizens and Permanent Residents Singapore NRIC should be entered as in the format SXXXXXXXXC or TXXXXXXXXC for those Singaporean born from 2000.
Passport No	Passport No. – Applicable to Foreigners only Enter passport no. if FIN no. is unavailable. Passport numbers enter as appears in the passport.
Foreign Identification (FIN) No.	FIN No. – Applicable to Foreigners only Enter FIN No. if patient has both FIN & Passport
Hospital Registration No.	Hospital Registration No.– Applicable to Foreigners and residents without NRIC
Date of Birth	Format is DD/MM/YYYY If only the year of birth is available then the date format will be 01/01/YYYY.
Date of Consultation	Enter the date (DD/MM/YYYY) of the latest consultation of the follow up year.
Healthcare Institution (including specific centre, department or clinic) responsible for subsequent treatment or follow-up	Enter the name of Hospital / Department / Clinic / Transplant centre where donor receives follow-up care.

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<b>Part V. DATA ITEMS ON YEARLY FOLLOW-UP FORM FOR KIDNEY DONOR</b>	
<b>Section 1. Particulars of donor (at follow-up)</b>	
<b>Data items</b>	<b>Definition</b>
Blood Pressure	Record systolic and diastolic blood pressure measurement in mmHg taken on the latest consultation of the follow up year. Tick - unknown if information is unavailable.
Weight	Record the latest measurement taken of the follow up year. Enter the date (DD/MM/YYYY) Tick - unknown if information is unavailable.
Smoking status	Based on status nearest to the date of consultation at the follow up year Tick accordingly: 1. Current Smoker 2. Ex-Smoker 3. Never 4. Unknown (information is unavailable)
Employment Status	Tick accordingly: Working full time, specify _____ Working part-time, specify _____ Not Working Retired Housewife Student Unknown (information is unavailable)
Complications within six weeks of discharge (following Nephrectomy)	1. Tick if No complication 2. If it is Renal Failure / Impairment: a) Enter the date of complication (DD/MM/YYYY) b) Enter the latest result and date of Serum Creatinine prior to diagnosis of renal failure / impairment. c) If Serum Creatinine is measured with IDMS standard, tick <input checked="" type="checkbox"/> 3. Or tick accordingly: <ul style="list-style-type: none"> <li>• Pulmonary Embolism</li> <li>• Wound Infection</li> <li>• Incisional pain</li> <li>• Others, specify _____</li> </ul>

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<b>Part V. DATA ITEMS ON YEARLY FOLLOW-UP FORM FOR KIDNEY DONOR</b>	
<b>Section 1. Particulars of donor (at follow-up)</b>	
<b>Data items</b>	<b>Definition</b>
Other Re-hospitalisation	State: <ul style="list-style-type: none"> <li>Reason for hospitalisation</li> <li>Duration of hospitalisation ( in days)</li> </ul>
EQ 5D (EuroQoL 5 dimensional format for health status)	Enter status of the following (on the EQ 5D form): - <ul style="list-style-type: none"> <li>Mobility</li> <li>Self-Care</li> <li>Usual Activities</li> <li>Pain/Discomfort</li> <li>Anxiety Depression</li> </ul> Tick - unknown if information is unavailable.
<b>Section 2. Risk factors (at follow-up)</b>	
Diabetes Mellitus	Tick: Yes /No/Unknown (Information is unavailable) <p>1.If diabetic:</p> <p>a) Indicate type of treatment : Diet / Oral hypoglycaemic / Insulin</p> <p>Enter HbA1C result _____%</p> <p>Enter the date (DD/MM/YYYY) of test.</p> <p>Tick - unknown if information is unavailable.</p> <p>2.If not Diabetic:</p> <p>Indicate if donor has –</p> <p><b>a) Impaired Fasting Glycemia</b></p> <p>This is when the fasting blood glucose is elevated above 'normal 'range but is not high enough to be classified as diabetes mellitus.</p> <p><u>Guideline:</u> Fasting plasma glucose <math>\geq 6.1</math> &amp; <math>&lt; 7.0</math> mmol/L or <math>\geq 110</math> &amp; <math>&lt; 126</math> mg/dl <b>and</b> 2 hr Plasma glucose during OGTT <math>&lt; 7.8</math> mmol/L or <math>&lt; 140</math> mg/dl</p> <p><b>b) Impaired Glucose Tolerance</b></p> <p>An intermediate stage of diabetes mellitus where: Fasting plasma glucose <math>&lt; 7.0</math> mmol/L or <math>&lt; 126</math> mg/dl <b>and</b> Two-hour plasma glucose during OGTT is <math>\geq 7.8</math> mmol or <math>\geq 140</math> mg /dL .</p> <p>Tick - unknown if information is unavailable.</p>

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**Part V. DATA ITEMS ON YEARLY FOLLOW-UP FORM FOR KIDNEY DONOR**

**Section 2. Risk factors (at follow-up)**

<b>Data items</b>	<b>Definition</b>
Hyperlipidemia	<p>Based on Dr's documentation nearest to the date prior to nephrectomy, tick accordingly:</p> <ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Unknown (Information is unavailable).</li> </ul> <p>Tick accordingly based on the results of :</p> <ul style="list-style-type: none"> <li>• LDL cholesterol    <input type="checkbox"/> Normal    <input type="checkbox"/> Elevated</li> <li>• Triglyceride        <input type="checkbox"/> Normal    <input type="checkbox"/> Elevated</li> </ul> <p>Tick - unknown if information (on blood test) is unavailable</p> <p>Enter the date (DD/MM/YYYY) of test</p>

**Section 3. Investigations (at follow-up)**

Fasting Blood Sugar	<p>Enter value in mmol/L</p> <p>Enter the date (DD/MM/YYYY) of test</p> <p>Tick - unknown if information is unavailable.</p>
Serum Creatinine	<p>Enter the value in umol or mg/dl</p> <p>Enter the date (DD/MM/YYYY) of test.</p> <p>If Serum Creatinine is measured with IDMS standard, tick <input checked="" type="checkbox"/></p> <p>Tick - unknown if information is unavailable</p>
Creatinine Clearance or Radionuclide GFR	<p>Enter the value in ml/min or ml/min 1.73m<sup>2</sup></p> <p>Enter the date (DD/MM/YYYY) of test.</p> <p>Tick - unknown if information is unavailable</p>
Urine FEME	<p>Record the measurement ( _ / hpf or _ / ul) of :</p> <p>RBC</p> <p>WBC</p> <p>Enter the date (DD/MM/YYYY) of test.</p> <p>Tick - unknown if information is unavailable</p>

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**Part V. DATA ITEMS ON YEARLY FOLLOW-UP FORM FOR KIDNEY DONOR**

**Section 3. Investigations (at follow-up)**

<b>Data items</b>	<b>Definition</b>
24 Hr Urine protein or Urine protein / creatinine ratio	Record the measurement for: <ul style="list-style-type: none"> <li>• 24 hr Urine Protein in g/day or mg/day or</li> <li>• Urine protein/creatinine ratio in g/g, mg/mg, mg/g or mg/mmol</li> </ul> Enter the date (DD/MM/YYYY) of test. Tick - unknown if information is unavailable

**Section 4. Medications (at follow-up)**

Anti-Hypertensive medication	Tick: Yes / No / Unknown If Yes, enter number of drugs donor is taking
Hypolipidemic drugs	Tick: Yes / No / Unknown If Yes, enter number of drugs donor is taking

**Part V. DATA ITEMS ON YEARLY FOLLOW-UP FORM FOR KIDNEY DONOR**

**5. Complications (at follow-up)**

Other illness since last visit	Tick: Yes / No / Unknown  If Yes, indicate one of the following: <ol style="list-style-type: none"> <li>a. Urinary tract disease</li> <li>b. Cardiovascular disease</li> <li>c. Cerebrovascular disease</li> <li>d. Pulmonary disease</li> <li>e. Musculoskeletal disease</li> <li>f. Malignancy</li> <li>g. Infection</li> <li>h. Accident</li> <li>i. Others, specify _____</li> </ol> Enter date (DD/MM/YYYY) of illness Refer to Annex A for examples of conditions classified under the various diseases/illnesses
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**Part V. DATA ITEMS ON YEARLY FOLLOW-UP FORM FOR KIDNEY DONOR**

**5. Complications (at follow-up)**

<b>Data items</b>	<b>Definition</b>
Admission to hospital since last visit	<p>Tick: Yes / No / Unknown</p> <p>Tick <input checked="" type="checkbox"/> if Day Surgery Admission</p> <p>If Yes, indicate reason for admission:</p> <ul style="list-style-type: none"> <li>a. Urinary tract disease</li> <li>b. Cardiovascular disease</li> <li>c. Cerebrovascular disease</li> <li>d. Pulmonary disease</li> <li>e. Musculoskeletal disease</li> <li>f. Malignancy</li> <li>g. Infection</li> <li>h. Accident</li> <li>i. Others, specify _____</li> </ul> <p>Enter date (dd/mm/yyyy) of admission</p> <p>Refer to Annex A for examples of conditions classified under the various diseases/illnesses</p>
CKD5 (Chronic Kidney Disease stage 5)	<p>Tick: Yes / No</p> <p>CKD (Chronic Kidney Disease) stage 5 which encompasses End Stage Renal Disease, is staged as kidney failure when -</p> <ul style="list-style-type: none"> <li>a) the Serum Creatinine has reached 5.7 mg/dl or <math>\geq 500 \mu\text{mol/L}</math>,</li> <li>b) the GFR (corrected to the body surface area of <math>1.73\text{m}^2</math>) is less than 15 ml/min</li> </ul> <p>OR</p> <ul style="list-style-type: none"> <li>c) when the patient has started Renal Replacement Therapy</li> </ul> <p>If yes, enter date (dd/mm/yyyy) of diagnosis</p> <p>CKD5 date – the earliest date of the GFR / eGFR which is less than 15 ml/min/<math>1.73 \text{m}^2</math></p>

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<b>Part V. DATA ITEMS ON YEARLY FOLLOW-UP FORM FOR KIDNEY DONOR</b>	
<b>5. Complications (at follow-up)</b>	
<b>Data items</b>	<b>Definition</b>
Cause of CKD5	State the primary renal disease which leads to CKD5 : e.g. Presumed GN – no biopsy  Refer to Annex B – List of codes for Primary Renal Diseases
On Transplant waiting list	Tick: Yes / No
Reason for not on Transplant waiting list	State the reason _____  Refer to ANNEX C – Reasons For Preclusion from Renal Transplant
<b>Part V. DATA ITEMS ON YEARLY FOLLOW-UP FORM FOR KIDNEY DONOR</b>	
<b>Section 6. Vital status</b>	
Vital Status	Tick either: Alive or Dead
Date of Death	Enter the date (DD/MM/YYYY) of death
Place of Death	Enter the place of death
Cause of Death	Enter the primary cause of death
<b>Section 7. Details of notifying healthcare institution</b>	
Name of notifying healthcare institution (including department)	Name of Hospital / clinic / transplant centre which made the notification
Name of notifying Person	Name of Doctor / Nurse who made the notification
Date of notification	Enter the date (DD/MM/YYYY )



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## **PART VI. DATA ITEMS ON LISTINGS**

### **Donor Case Listing - Listing of Live Donors who have had Nephrectomy**

	<b>Particulars of Donor</b>
1	Name
2	NRIC/Passport/FIN/Hospital No.
3	Date of Birth
4	Gender
5	Ethnic group
6	Marital status
7	Resident status
8	Education level
9	Employment status
10	Date of Nephrectomy
11	Place of Nephrectomy
12	Type of Nephrectomy
13	Name of Lead Surgeon
14	Living Donor's Relationship to Recipient
15	Name of notifying healthcare institution (including department)
	<b>Particulars of Recipient</b>
16	Name
17	NRIC/Passport/FIN/Hospital No.
18	Date of Birth
19	Gender
20	Place of Transplantation

### **Listing of Hospital Inpatient Discharge summaries**

1	Name Of Donor
2	Donor's NRIC/Passport/FIN/Hospital No.
3	Date of Birth
4	Gender
5.	Name of notifying healthcare institution (including department)
6.	Date of Admission
7.	Date of Discharge
8.	Diagnosis at discharge
9.	V Codes: V59.4 for Kidney Donors

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**Annex A - Examples of conditions classified under the various diseases/illnesses (list is not exhaustive)**

<b>Urinary Tract Disease</b>	<b>Cardiovascular Disease</b>	<b>Cerebrovascular Disease</b>
Bladder Infection	AAA (Abdominal Aortic Aneurysm)	Basal Ganglia Cerebrovascular Disease
BPH (Benign Prostatic Hyperplasia)	Acute Myocardial Infarction	Dementia, Vascular
Cystitis	Cardiac Failure	Hemorrhagic Stroke
Glomerulonephritis (GN)	Cardiomyopathy	Intracranial Embolism and Thrombosis
Hematuria	Congestive Heart Failure	Ischaemic Stroke
Hydrocele	Coronary Artery Disease	Lacunar Infarct
Nephrolithiasis (Kidney Stone)	Endocarditis	Transient Ischaemic Attack
Nephrotic Syndrome	Hypercholesterolemia / Hyperlipidemia	Vascular Headaches
Proteinuria	Hypertension	
Pyelonephritis	Ischaemic Heart Disease	
Urethral Stricture	Peripheral Vascular Disease	
Urethritis		
Urolithiasis (Urinary Stone)		
UTI (Urinary Tract Infections)		
<b>Pulmonary Disease</b>	<b>Musculoskeletal Disease</b>	<b>Malignancy</b>
Asthma	Back Pain	Leukemia
Bronchopneumonia	Bone Diseases	Malignant Neoplasm of Breast
Bronchitis	Fasciitis	Malignant Neoplasm of Cervix
COLD/COPD (Chronic Obstructive Lung Disease / Chronic Obstructive Pulmonary Disease)	Gout	Malignant Neoplasm of Colon
Emphysema	Joint Diseases	Malignant Neoplasm of Esophagus
Pleural Effusion	Joint Pain	Malignant Neoplasm of Kidney
Pneumonia	Lumbago	Malignant Neoplasm of Larynx
Pneumothorax	Osteoarthritis	Malignant Neoplasm of Liver
PTB	Osteoporosis	Malignant Neoplasm of Lung
	Rheumatic Diseases	Malignant Neoplasm of Nasopharynx
	Spinal Stenosis	Malignant Neoplasm of Prostate
	Systemic Lupus Erythematous (SLE)	Malignant Neoplasm of Stomach
		Malignant Neoplasm of Tongue
		Malignant Neoplasm of Uterus
		Multiple Myeloma
		Lymphoma

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**Annex A - Examples of conditions classified under the various diseases/illnesses (list is not exhaustive) continuation**

<b>Infection</b>	<b>Accident</b>	
Chickenpox	Drug Overdose	
CMV (Cytomegalovirus) Disease	Falls	
Dengue Fever	Industrial Accident	
Gastroenteritis	Road Traffic Accident	
Hand,foot and mouth disease	Sporting accident	
HIV Infection		
Malaria		
Meningitis		
Septicaemia		
Surgical Wound Infection		
Viral Hepatitis		

**ANNEX B: LIST OF CODES FOR PRIMARY RENAL DISEASES**

<b>Code</b>	<b>Disease Description</b>
<b>0000</b>	ESRD – Unknown
<b>0100</b>	Amyloid Glomerulopathy
<b>0350</b>	Diabetic Nephropathy
<b>0400</b>	Drug Induced Glomerulopathy incl heroin
<b>1000</b>	Presumed GN – no biopsy
<b>1010</b>	GN – biopsy: Sclerosing GN
<b>1011</b>	GN – biopsy: Inconclusive
<b>1020</b>	GN – Minimal Lesion
<b>1021</b>	IgM Nephropathy
<b>1100</b>	Focal Sclerosing GN: Focal Segmental Hyalinosis
<b>1101</b>	Focal Global Sclerosis
<b>1102</b>	Focal & Segmental Glomerulosclerosis
<b>1103</b>	Focal Segmental Hyalinosis
<b>1210</b>	Mesangio-capillary/Membrano-proliferative Type I (DDD)
<b>1220</b>	Mesangio-capillary/Membrano-proliferative Type II (DDD)
<b>1300</b>	Membranous (epimembranous) Glomerulonephritis
<b>1400</b>	Crescentic GN (otherwise not specified): RPGN

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## **ANNEX B: LIST OF CODES FOR PRIMARY RENAL DISEASES (continuation)**

<b><u>Code</u></b>	<b><u>Disease Description</u></b>
<b>1500</b>	IgA Mesangial Proliferative (IgA)
<b>1501</b>	IgA Minimal Lesion
<b>1502</b>	IgA Focal Mesangial GN
<b>1503</b>	IgA Diffuse Mesangial GN
<b>1504</b>	IgA Crescentic GN
<b>1505</b>	IgA Diffuse Sclerosing GN
<b>1509</b>	IgA Unspecified/Inconclusive
<b>1510</b>	Mesangial Proliferative (non IgA)
<b>1511</b>	Mesangial Proliferative GN (No IMF)
<b>1520</b>	Henoch-Scholein GN
<b>1530</b>	Focal Segmental Proliferative (include Focal Necrosis)
<b>1600</b>	Goodpasture (anti-GBM with lung involvement)
<b>1610</b>	Proliferative GN with anti-GBM (no lung involvement)
<b>1620</b>	Proliferative GN with lung involvement (not Goodpasture)
<b>1630</b>	Wegener (extra renal granuloma proven)
<b>1640</b>	Polyarteritis Nodosa (macrovascular)
<b>1650</b>	Polyarteritis Nodosa (microvascular)
<b>1660</b>	ANCA positive GN
<b>1670</b>	HBsAg associated GN
<b>1680</b>	HIV Nephropathy
<b>1700</b>	Systemic Lupus Erythematosus – Unspecified
<b>1701</b>	SLE Class 1 – Normal Glomeruli
<b>1702</b>	SLE Class 2 – Pure Mesangial Alterations (Mesangiopathy)
<b>1703</b>	SLE Class 3 – Focal Segmental Glomerulonephritis (associated with mild or moderate mesangial alterations)
<b>1704</b>	SLE Class 4 – Diffuse Glomerulonephritis (severe mesangial, endocapillary or mesangial-capillary proliferation and/or extensive subendothelial deposits)
<b>1705</b>	SLE Class 5 – Diffuse Membranous Glomerulonephritis
<b>1706</b>	SLE Class 6 – Advanced Sclerosing Glomerulonephritis
<b>1710</b>	Scleroderma
<b>1720</b>	GN with other Systemic/Rheumatoid Disease

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## **ANNEX B: LIST OF CODES FOR PRIMARY RENAL DISEASES (continuation)**

<b><u>Code</u></b>	<b><u>Disease Description</u></b>
<b>1800</b>	Inherited Glomerulopathy (Unspecified)
<b>1810</b>	Alport's Disease (Classical)
<b>1820</b>	Fabry's Disease
<b>1830</b>	Oxalosis
<b>1840</b>	Cystinosis
<b>1900</b>	Other biopsied GN
<b>2000</b>	Analgesic Nephropathy
<b>2010</b>	Drug-Induced Interstitial Nephritis
<b>2020</b>	Lead Nephropathy
<b>2030</b>	Other Heavy Metal Nephropathy
<b>3000</b>	Acquired Obstructive Uropathy (otherwise unspecified)
<b>3010</b>	Renal/Ureteric/Bladder Calculi
<b>3020</b>	Renal Calculi (urate)
<b>3030</b>	Retroperitoneal Fibrosis
<b>3040</b>	Bladder Neck Obstruction (include Prostatomegaly)
<b>4000</b>	Congenital Obstructive Uropathy Renal Tract Anomaly (Unspecified)
<b>4010</b>	Posterior Urethral Valves (Obstructive Nephropathy)
<b>4020</b>	Megacystis-Megaureter
<b>4030</b>	Prune-Belly Syndrome
<b>4040</b>	PUJ Obstruction
<b>4050</b>	Renal Anomaly with Spina Bifida/Myelomeningocele
<b>4060</b>	Renal Hypoplasia/Dysplasia/Agensis
<b>4070</b>	Neuropathic Bladder (Congenital or Acquired)
<b>4080</b>	Vesicoureteric Reflex (Reflux Nephropathy)
<b>5000</b>	Chronic Pyelonephritis (otherwise unspecified)
<b>5010</b>	Renal TB
<b>5020</b>	Schistosomiasis (Bilharzial Disease)
<b>5030</b>	Interstitial Nephritis (otherwise unspecified)
<b>6000</b>	Acute Cortical Necrosis (otherwise unspecified)
<b>6010</b>	Acute Cortical Necrosis (post-obstetric)
<b>6020</b>	Hemolytic Uremic Syndrome

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**ANNEX B: LIST OF CODES FOR PRIMARY RENAL DISEASES (continuation)**

<b><u>Code</u></b>	<b><u>Disease Description</u></b>
<b>6030</b>	Thrombotic Thrombocytopenic Purpura
<b>7000</b>	Adult Polycystic Disease
<b>7010</b>	Infantile/Juvenile Polycystic Disease
<b>7020</b>	Medullary Cystic Disease (Nephronophthisis)
<b>8000</b>	Renal Vascular Disease (otherwise unspecified)
<b>8010</b>	Renal Vascular Disease (Malignant Hypertensive Nephroscl: no Primary Renal Dx)
<b>8020</b>	Renal Vascular Disease (Hypertensive Nephropathy)
<b>8030</b>	Renal Artery Stenosis (RAS: unspecified)
<b>8040</b>	RAS (Fibromuscular Hyperplasia)
<b>8050</b>	RAS (Atherosclerotic/Arteriosclerotic)
<b>8060</b>	Cholestrol Emboli
<b>9000</b>	Renal Cell Carcinoma
<b>9010</b>	Wilm's Tumour
<b>9020</b>	Transitional Cell Carcinoma
<b>9030</b>	Paraproteinemia (include Multiple Myeloma)
<b>9039</b>	Other Malignant involvement of the kidney
<b>9040</b>	Traumatic/Surgical Loss - single functioning kidney
<b>9999</b>	Diagnosis Not Listed (specify) _____

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## **ANNEX C: REASONS FOR PRECLUSION FROM RENAL TRANSPLANT**

<b><u>Code</u></b>	<b><u>Description</u></b>
<b>01</b>	As yet unassessed/awaiting assessment
<b>10</b>	High Cytotoxic Antibody Level
<b>20</b>	Recipient Refusal
<b>30</b>	Technical problems – Urological
<b>31</b>	Technical problems – Vascular
<b>40</b>	Recurrent disease previous graft
<b>41</b>	Multiple loss previous grafts
<b>50</b>	Active Infection
<b>60</b>	Medically Unfit (Unspecified)
<b>70</b>	Preclusive Respiratory Disease
<b>71</b>	Preclusive Cardiac Disease
<b>72</b>	Preclusive Hepatic Disease
<b>73</b>	Preclusive Cerebral/ Cerebrovascular Disease
<b>74</b>	Preclusive Psychological/ Psychiatric Disease
<b>75</b>	Preclusive Malignant Disease
<b>76</b>	Preclusive Metabolic/ Endocrine Disease
<b>77</b>	Preclusive Intestinal Disease (non-malignant)
<b>80</b>	Systemic Lupus Erythematosus – serological active
<b>81</b>	Systemic Lupus Erythematosus – clinically active
<b>82</b>	Anti – GBM antibodies
<b>83</b>	ANCA positive
<b>84</b>	Immunological Systemic Disease – Active (non – SLE)
<b>85</b>	Renal Disease high likelihood of recurrence
<b>90</b>	Age Limitation
<b>91</b>	Financial Limitation
<b>95</b>	Had a functioning graft – Not Applicable
<b>99</b>	Other – non medical restriction