

Guidelines

Document Title: Liver-Post Hepatic Resection (Donor) Registration

Guidelines

Document No: NRDO-G001.05b

Document Class: Restricted

Version no: 2.2

Effective Date: 01 APRIL 2011

NATIONAL REGISTRY OF DISEASES	Document No:	NRDO-G001.05b
Liver-Post Hepatic Resection (Donor) Registration Guidelines	Effective Date:	01 APRIL 2011 (Ver 2.2)

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ABBREVIATIONS

DCR Donor Care Registry

sFTP secured File Transfer Protocol (Secured way for electronic data

transmission)

PGP Pretty Good Privacy (Software for encrypting data in emails)

NRD National Registry of Diseases

NRDO National Registry of Diseases Office

NOTU National Organ Transplant Unit

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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 liverpost hepatic resection (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 hepatic resection for the purpose of transplantation into the body of another living person

or

 b) the donor is undergoing treatment for liver- post hepatic resection at the healthcare institution (first of such treatments received by the donor at the healthcare institution on or after 1st November 2009).

The Advisory Committee on Transplant (ACT) has recommended follow up treatment for liver-post hepatic resection (donor) at 6-week, 3-month, 6-month after hepatic resection and 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 liver- post hepatic resection (donor).

Part II. DEFINITION

"hepatic resection" means the surgical removal of a part of the liver

"liver – post hepatic resection (donor)" refers to the absence of a part of liver in a person due to having undergone hepatic resection for the purpose of transplantation of a part of his liver 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 (Liver-Post Hepatic Resection (Donor) Notification)
Regulations 2009 relates (i.e. the donor):

"recipient" means the person into whose body a part of the patient's liver 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 hepatic resection and upon commencement of follow-up treatment at any healthcare institution.

TABLE 1: Pathways and Timeline of reporting

a) REPORTING OF NEW CASE OF LIVER DONATION		
Pathways of Notification	Timeline	Mode of data transmission
New cases of liver donors For all new cases of liver transplantation reported to NOTU - there is no need to further notify NRDO of these new cases. Form of notification:- Donor case listing - will be submitted by the National Organ Transplant unit (NOTU) to NRDO to fulfil the requirements for healthcare institutions to report new cases under the NRD Act.	Routine monthly reports from NOTU	sFTP

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a) REPORTING OF NEW CASE OF LIVER DONATION			
Pathways of Notification	Timeline	Mode of data transmission	
For New cases of Liver transplantation not reported to NOTU:	Within 3 months from date of hepatic resection for organ donation.	(1) E- Notification @ the Health Professional Portal (www.hpp.moh.gov.sg) (This is an on-line notification system for doctors to notify	
Form to use: - New Case Registration Form for Liver Donor		reportable diseases/conditions)	
		or	
		(2) Hard copy can be downloaded from Registry's Internet website @ http://www.nrdo.gov.sg or requested from the National Registry of Diseases Office (NRDO) and then sent by Registered mail or by hand (including courier service) to: Donor Care Registry at the NRDO	
		N.B. Please DO NOT submit the form via email or fax.	

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b) REPORTING OF TREATMENT OR FOLLOW-UP OF DONOR			
Pathways of Notification	Timeline	Mode of data transmission	
For Donor undergoing treatment post hepatic resection (first of such treatment on or after 1 st November 2009) at the healthcare institution: Form to use: - Follow-up Form for Liver Donor	Within 3 months after the treatment has commenced at the healthcare institution i.e. • Private specialist clinic, • Specialist outpatient clinic at Restructured Hospitals	(1) E- Notification @ the Health Professional Portal (www.hpp.moh.gov.sg) Or (2) Hard copy can be downloaded from Registry's Internet website @ http://www.nrdo.gov.sg or requested from the National Registry of Diseases Office (NRDO) and then sent by Registered mail or by hand (including courier service) to: Donor Care Registry at the NRDO N.B. Please DO NOT submit the form via email or fax.	
For donors who are admitted to Restructured hospitals for inpatient treatment subsequent to post hepatic resection: Hospital Inpatient Discharge summaries listing	Within 3 months after the hospitalisation	(1) sFTP or PGP or encrypted electronic storage device e.g. thumb drive, CD rom. or (2) Hardcopy listing - and sent by Registered mail or by hand (including courier service) to: Donor Care Registry at the NRDO	

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Minimal mandatory data items

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

- 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 hepatic resection (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
- or
- b) by completing the following forms (hardcopy):
 - i) New Case New Case Registration form for Liver Donor
 - ii) Follow-Up treatment Follow-Up treatment form
- Note: Hardcopy form must be delivered to NRDO via Registered mail or hand delivered

Updates on follow-up treatment

Information on the donor's well-being post hepatic resection will be collected at the recommended scheduled intervals of six weeks, three months and six months after hepatic resection and then at year-end (which will commence in the month of December).

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

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The following table provides definitions for the data items on the New Case Registration form for Liver Donor:

Section 1: Particulars of Donor		
Data items	Definition	
Name	Record the patient's name (underline surname) from NRIC/ Passport/employment pass/work permit /Birth certificate/case-notes.	
NRIC Passport No	NRIC No. } – Applicable to Singapore citizens and Permanent Residents Singapore NRIC should be entered as in the format SXXXXXXXC or TXXXXXXXC for those Singaporean born from 2000. Passport No. – Applicable to Foreigners only Enter passport no. if FIN no. is unavailable.	
Foreign Identification (FIN) No.	Passport numbers enter as appears in the passport. 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), please specify or select from the 'drop down' list (E notification).	
Gender	Tick accordingly: Male or Female	

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Section 1: Particulars of Donor			
Data items	Definition		
Country of Birth	Patient's country of birth 1. Singapore 2. Malaysia 3. China 4. Indonesia 5. India 6. Others, specify: 7. Unknown		
Ethnic Group	 Tick - Chinese / Malay / Indian / Eurasian /Others Malay – refers to persons of Malay or Indonesian origin. Eg: Boyanese, Bugis, Javanese. Indian – Include people from India and India subcontinent. Eg: Bangladeshi, Bengali, Malayal Punjabi, Sikhs, Singhalese, Sri Lankans and Tam Eurasian – refers to mixed ancestry Others – refers to groups not classified as above Eg: Arab, Caucasian, Japanese, etc. Please spector select from drop-down list (E notification). 		
Marital Status	Tick accordingly: 1. Single 2. Married 3. Widowed 4. Separated 5. Divorced 6. Unknown (information is unavailable)		

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Section 1: Particulars of Donor		
Data items	Definition	
Educational level (Highest)	For those born between 1920s and 1940s, can code as: 'No Formal' or 'Low Primary' if information on education is unavailable.	
	Tick accordingly: No Formal Education Low Primary PSLE Secondary (No 'O' level certificate) GCE N Level GCE-O Level GCE-A Level Diploma University & above Not Available	
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, specify B. Emotionally related Spouse	
	Friend Others, specify C. Others Directed (Donor knows who is the recipient) Non- Directed (Donor does not know the recipient) Others, specify	

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Section 2: Particulars of Recipient		
Data items	Definition	
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 SXXXXXXXC or TXXXXXXXC for those Singaporean born from 2000.	
Passport No Foreign Identification (FIN) No.	Passport No. – Applicable to Foreigners only Enter passport no. if FIN no. is unavailable. Passport numbers enter as appears in the passport. 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 5 – Others (refers to foreigners with other types of visa), please specify or select from the 'drop down' list (E notification).	
Gender	Tick accordingly: Male or Female	

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Section 2: Particulars of Recipient			
Data items	Definition		
Ethnic Group	Tick - Chinese / Malay / Indian / Eurasian /Others		
	Malay – refers to persons of Malay or Indonesian origin. E.g.: Boyanese, Bugis, Javanese.		
	Indian — Include people from India and India subcontinent. E.g.: Bangladeshi, Bengali, Malayalee, Punjabi, Sikhs, Singhalese, Sri Lankans and Tamil.		
	Eurasian – refers to mixed ancestry		
	Others – refers to groups not classified above. E.g.: Arab, Caucasian, Japanese, etc. Please specify or select from drop-down list (E notification).		
Marital Status	Tick accordingly: 1. Single 2. Married 3. Widowed 4. Separated 5. Divorced 6. Unknown (information is unavailable)		
Name of Recipient's Healthcare Institution	Place where transplantation was performed: Tick accordingly: Singapore General Hospital National University Hospital Gleneagles Hospital Mount Elizabeth Hospital Raffles Hospital Others, specify		

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Data items	Definition
Date of Baseline information	Date format DD/MM/YYYY Date of latest consultation prior to hepatic resection.
Weight	Record the latest measurement taken and date prior to hepatic resection.
	Date format DD/MM/YYYY
	Tick - unknown if information is unavailable.
Height	Record the latest measurement taken and date prior to hepatic resection.
	Date format DD/MM/YYYY
	Tick - unknown if information is unavailable.
Smoking status	Based on status nearest to the time of hepatic resection. Tick accordingly: 1. Current Smoker 2. Ex-Smoker 3. Never
	Unknown (information is unavailable)
EQ 5D (EuroQol 5 dimensional format	Enter status of the following (on the EQ 5D form): - • Mobility
for health status)	Self-Care
	Usual Activities
	Pain/Discomfort
	Anxiety Depression
	Tick - unknown if information is unavailable.

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Section 3: Donor Baseline Information (Pre - Donation)		
Data items	Definition	
Liver Panel	Enter the date (DD/MM/YYYY) of test and all results of the various components. Tick - unknown if information is unavailable.	
Full Blood Count	Enter the date (DD/MM/YYYY) of test and all results of the various components. Tick - unknown if information is unavailable.	
Prothrombin Time (PT)	Enter the date (DD/MM/YYYY) of test and all results. Tick - unknown if information is unavailable.	
Ultrasound / CT scan / MRI Liver		
Olliasodilu / CT Scall / Wilki Livei	Enter the date (DD/MM/YYYY) of test and findings Tick accordingly: No abnormalities Fatty Liver Other abnormalities, specify	
	Tick - unknown if information is unavailable	
Section 4: Data Related to Donor Hepatic Res	ection	
Date of hepatic resection	Enter the date (DD/MM/YYYY) of surgery	
Place of surgery	Tick accordingly: Singapore General Hospital National University Hospital Gleneagles Hospital Mount Elizabeth Hospital Raffles Hospital Others, specify	
Type of hepatic resection	Specify the type of hepatic resection.	

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Section 4: Data Related to Donor Hepatic Resection		
Data items	Definition	
Complications during hospitalisation	Tick NO if there is nil complication Tick accordingly for Liver Failure/Impairment NO Unknown (information is unavailable) if Yes, enter the date of Liver failure/impairment (DD/MM/YYYY) Or Tick Surgical / Medical / Others and specify the condition	
Date of initial discharge	Enter the date (DD/MM/YYYY) of discharge	
Live donor discharge disposition	Tick either: Alive or Dead	
Section 5: Details of notifying healthcare institu	 ution	
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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The following table provides definitions for the data items on the Follow-up form for Liver donor based on the recommended scheduled interval of 6/52, 3/12 and 6/12 after hepatic resection and then annually (which will be collected at year-end).

Data items	Definition
Section 1: Donor's status at follow-up	
Name	Record the patient's name (underline surname) from NRIC/ Passport/case-notes/Birth certificate/employment pass/work permit.
NRIC	NRIC No. } – Applicable to Singapore citizens and Permanent Residents Singapore NRIC should be entered as in the format SXXXXXXXC or TXXXXXXXXC for those Singaporean born from 2000.
Passport No	Passport No. – Applicable to Foreigners only
Foreign Identification (FIN) No.	Enter passport no. if FIN no. is unavailable. Passport numbers enter as appears in the passport.
. Grough radinaneauton (r my rudi	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 last consultation, nearest to the recommended follow-up at 6/52, 3/12 and 6/12 or annually after the hepatic resection.
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.
Height	Record the latest measurement taken Enter the date (DD/MM/YYYY) Tick - unknown if information is unavailable.

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Section 1: Donor's status at follow-up		
Data items	Definition	
Weight	Record the latest measurement taken on or nearest to the date of consultation. Enter the date (DD/MM/YYYY) Tick - unknown if information is unavailable.	
Smoking status	Based on status recorded, nearest the date of consultation. 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)	
EQ 5D (EuroQol 5 dimensional format for health status)	Enter status of the following (on the EQ 5D form): - • Mobility • Self-Care • Usual Activities • Pain/Discomfort • Anxiety Depression Tick - unknown if information is unavailable.	

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Section 1: Donor's status at follow-up			
Data items	Definition		
Other illness since last visit	Tick: Yes / No / Unknown		
	If Yes, tick one of the following:		
	a. Urinary tract disease		
	b. Cardiovascular disease		
	c. Cerebrovascular disease		
	d. Pulmonary disease		
	e. Musculoskeletal disease		
	f. Malignancy		
	g. Infection		
	h. Accident		
	i. Others, specify		
	Enter date (DD/MM/YYYY) of illness		
	Refer to Annex A for examples of conditions classified under the various diseases/illnesses		
Admission to hospital since last visit	Tick: Yes / No / Unknown		
	Tick ☐ if Day Surgery Admission		
	If Yes, tick one of the following:		
	a. Urinary tract disease		
	b. Cardiovascular disease		
	c. Cerebrovascular disease		
	d. Pulmonary disease		
	e. Musculoskeletal disease		
	f. Malignancy		
	g. Infection		
	h. Accident		
	i. Others, specify		
	Enter date (dd/mm/yyyy) of admission		
	Refer to Annex A for examples of conditions classified under the various diseases/illnesses		

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Section 2: investigations (at follow-up)		
Data items	Definition	
Liver Panel	Enter the date (DD/MM/YYYY) of test. and all results of the various components.	
	Tick - unknown if information is unavailable.	
Full Blood Count	Enter the date (DD/MM/YYYY) of test and all results of the various components.	
	Tick - unknown if information is unavailable.	
Prothrombin Time (PT)	Enter the date (DD/MM/YYYY) of test and all results.	
	Tick - unknown if information is unavailable.	
Ultrasound Liver	Enter the date (DD/MM/YYYY) of test and Tick accordingly: No abnormalities Fatty Liver Other abnormalities, specify	
	Tick - unknown if information is unavailable.	
CT Scan / MRI Liver	Enter the date (DD/MM/YYYY) of test and findings Tick accordingly: No abnormalities Fatty Liver Other abnormalities, specify	
	Tick - unknown if information is unavailable.	
ERCP/MRCP	Enter the date (DD/MM/YYYY) of test and findings Tick accordingly: • .ERCP: • MRCP: • Others, specify	
	Tick - unknown if information is unavailable.	

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Section 3: Adverse condition relating to liver			
Data items	Definition		
Liver Failure	Tick: Yes / No		
Date of Liver Failure	If Yes, enter the date (DD/MM/YYYY) of diagnosis		
Cause of Liver Failure	State the cause of the condition		
On Transplant waiting list	Tick: Yes / No		
Reason for not on Transplant waiting list	State the reason		
Section 4: Vital Status			
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		
Section 5: Details of notifying healthcare institu	ution		
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

	Particulars of Donor	
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 Hepatic Resection	
11	Place of Hepatic Resection	
12	Type of Hepatic Resection	
13	Living Donor's Relationship to Recipient	
14	Name of notifying healthcare institution (including department)	
	Particulars of Recipient	
15	Name	
16	NRIC/Passport/FIN/Hospital No.	
17	Date of Birth	
18	Gender	
19	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: V59.6 for Liver Donors

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

Urinary Tract Disease	Cardiovascular Disease	Cerebrovascular Disease
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)		
Pulmonary Disease	Musculoskeletal Disease	Molignanov
Asthma	Back Pain	Malignancy Leukemia
	Bone Diseases	
Bronchopneumonia Bronchitic		Malignant Neoplasm of Breast
Bronchitis	Fasciitis	Malignant Neoplasm of Cervix
COLD/COPD (Chronic Obstructive Lung Disease/Chronic Obstructive Pulmonary Disease)	Gout	Malignant Neoplasm of Colom
mphysema	Joint Diseases	Malignant Neoplasm of Esophagus
Pleural Effusion	Joint Pain	Malignant Neoplasm of Kidney
Pneumonia	Lumbago	Malignant Neoplasm of Layrnx
Pneumothorax	Osteoarthritis	Malignant Neoplasm of Liver
РТВ	Osteoporosis	Malignant Neoplasm of Lung
	Rheumatic Diseases	Malignant Neoplasm of Nasopharynx
	Spinal Stenosis	Malignant Neoplasm of Prostate
		Malignant Neoplasm of Stomach
		Malignant Neoplasm of Tongue
		Malignant Neoplasm of Uterus
		Multiple Myeloma
		Lymphoma

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Annex A - Other Illnesses/Admissions since last visit Listing (sample list and is not exhaustive) continuation

Infection	Accident	
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		