

# 1

## NEW PATIENT REGISTRATION FORM

(Complete once only, on first entry of the patient into the Registry)

<b>Form completion date</b>										
<b>ID number</b> (or passport no.)										
<b>Last name</b>	<b>First Name:</b>									
<b>DOB</b>	(dd Month yyyy)					<b>Gender:</b>	Male <input type="checkbox"/>	Female <input type="checkbox"/>		
<b>Ethnicity</b>	Black <input type="checkbox"/>	Coloured <input type="checkbox"/>	Indian/Asian <input type="checkbox"/>	White <input type="checkbox"/>	Other: <input type="checkbox"/>					
<b>City of residence</b>						<b>Country (citizenship):</b>				
<b>Province of residence</b>	East Cape <input type="checkbox"/>	Free State <input type="checkbox"/>	Gauteng <input type="checkbox"/>	KZN <input type="checkbox"/>	Limpopo <input type="checkbox"/>	Mpumalanga <input type="checkbox"/>	North West <input type="checkbox"/>	North Cape <input type="checkbox"/>	West Cape <input type="checkbox"/>	
<b>Date started RRT</b>	(date of first dialysis or transplant, dd Month yyyy)									
<b>FIRST modality</b> (How was RRT started?)	Haemodialysis <input type="checkbox"/>	Peritoneal Dialysis <input type="checkbox"/>	Transplant <input type="checkbox"/>	Unknown <input type="checkbox"/>						
<b>CURRENT modality</b>	<input type="checkbox"/> Haemodialysis	<input type="checkbox"/> HDF	<input type="checkbox"/> Home HD	<input type="checkbox"/> CAPD	<input type="checkbox"/> APD	<input type="checkbox"/> Transplant				
<b>Current Rx Unit</b>										
<b>Sector</b>	Public sector <input type="checkbox"/>	Private <input type="checkbox"/>	Public-Private Initiative <input type="checkbox"/>							
<b>Treating Doctor</b>										
<b>Renal diagnosis</b> (primary renal disease causing ESRD)	<input type="checkbox"/> ESRD cause unknown	<input type="checkbox"/> Diabetic nephropathy	<input type="checkbox"/> Glomerulonephritis							
	<input type="checkbox"/> Malignant hypertension	<input type="checkbox"/> Cystic kidney disease	<input type="checkbox"/> Other (give details)							
	<u>Diagnosis details:</u>									
	<input type="checkbox"/> Diagnosis histologically proven									<input type="checkbox"/> Diagnosis NOT histologically proven

### Comorbidity at START of renal replacement therapy

<b>Diabetes status</b>	Not diabetic <input type="checkbox"/>	Unknown <input type="checkbox"/>	Type 1 DM <input type="checkbox"/>	Type 2 DM <input type="checkbox"/>	Diabetic, type unknown <input type="checkbox"/>
<b>Hep B status</b>	<input type="checkbox"/> Negative	<input type="checkbox"/> Immune	<input type="checkbox"/> Positive	<input type="checkbox"/> Unknown	
<b>Hep C status</b>	<input type="checkbox"/> Negative	<input type="checkbox"/> Positive	<input type="checkbox"/> Unknown		
<b>HIV status</b>	<input type="checkbox"/> Negative	<input type="checkbox"/> Positive	<input type="checkbox"/> Unknown		

# 2

## PATIENT ANNUAL ASSESSMENT FORM

(Data as at 31 December, or closest available data)

<b>ID number</b> (or passport no.)		<b>Assessment date:</b>							
<b>Last name</b>	<b>First Name:</b>								
<b>City of residence</b>									
<b>Province of residence</b>	East Cape <input type="checkbox"/>	Free State <input type="checkbox"/>	Gauteng <input type="checkbox"/>	KZN <input type="checkbox"/>	Limpopo <input type="checkbox"/>	Mpumalanga <input type="checkbox"/>	North West <input type="checkbox"/>	North Cape <input type="checkbox"/>	West Cape <input type="checkbox"/>
<b>CURRENT modality</b>	<input type="checkbox"/> Haemodialysis <input type="checkbox"/> HDF <input type="checkbox"/> Home HD		<input type="checkbox"/> CAPD <input type="checkbox"/> APD		<input type="checkbox"/> Transplant				
<b>Current Rx Unit</b>									
<b>Sector</b>	<input type="checkbox"/> Public sector			<input type="checkbox"/> Private sector			<input type="checkbox"/> Public-Private Initiative		
<b>Doctor</b>									

### Comorbidity – CURRENT status

<b>Diabetes status</b>	Not diabetic <input type="checkbox"/>	Unknown <input type="checkbox"/>	Type 1 DM <input type="checkbox"/>	Type 2 DM <input type="checkbox"/>	Post-transplant DM <input type="checkbox"/>	Diabetic, but type unknown <input type="checkbox"/>
<b>Hep B status</b>	<input type="checkbox"/> Negative <input type="checkbox"/> Immune		<input type="checkbox"/> Positive		<input type="checkbox"/> Unknown	
<b>Hep C status</b>	<input type="checkbox"/> Negative		<input type="checkbox"/> Positive		<input type="checkbox"/> Unknown	
<b>HIV status</b>	<input type="checkbox"/> Negative		<input type="checkbox"/> Positive		<input type="checkbox"/> Unknown	

### Additional information for patients on dialysis only

<b>Albumin (g/l):</b>
<b>Haemoglobin (g/dl):</b>
<b>Number of HD sessions/week (HD patients only):</b>

# 3

## TRANSPLANT PROCEDURE FORM

<b>ID number</b> (or passport no.)			<b>Transplant date:</b>						
<b>Patient last name</b>	<b>First name:</b>								
<b>City of residence</b>									
<b>Province of residence</b>	East Cape <input type="checkbox"/>	Free State <input type="checkbox"/>	Gauteng <input type="checkbox"/>	KZN <input type="checkbox"/>	Limpopo <input type="checkbox"/>	Mpumalanga <input type="checkbox"/>	North West <input type="checkbox"/>	North Cape <input type="checkbox"/>	West Cape <input type="checkbox"/>
<b>Transplant centre</b>									
<b>Sector</b>	<input type="checkbox"/> Public sector		<input type="checkbox"/> Private sector		<input type="checkbox"/> Public-Private Initiative				
<b>Doctor</b>	(responsible nephrologist)								
<b>Type of organ</b>	<input type="checkbox"/> Kidney	<input type="checkbox"/> Kidney-pancreas		<input type="checkbox"/> Kidney-liver					
<b>Transplant number</b>	(Indicate whether this is the first or subsequent transplant)								
<b>Donor type</b>	<input type="checkbox"/> Deceased donor								
	<input type="checkbox"/> Living related donor	<input type="checkbox"/> Living donor, not related		<input type="checkbox"/> Living donor, unknown if related					
<b>Prior RRT modality</b>	<input type="checkbox"/> CKD (not yet on dialysis)		<input type="checkbox"/> HD	<input type="checkbox"/> PD					

### Comorbidity – current status

<b>Diabetes status</b>	Not diabetic <input type="checkbox"/>	Unknown <input type="checkbox"/>	Type 1 DM <input type="checkbox"/>	Type 2 DM <input type="checkbox"/>	Post-transplant DM <input type="checkbox"/>	Diabetic, type unknown <input type="checkbox"/>	
<b>Hep B status</b>	<input type="checkbox"/> Negative		<input type="checkbox"/> Immune		<input type="checkbox"/> Positive		<input type="checkbox"/> Unknown
<b>Hep C status</b>	<input type="checkbox"/> Negative			<input type="checkbox"/> Positive		<input type="checkbox"/> Unknown	
<b>HIV status</b>	<input type="checkbox"/> Negative			<input type="checkbox"/> Positive		<input type="checkbox"/> Unknown	

# 4

## PATIENT TRANSFER AND STOPPED TREATMENT FORM

Last name

First name:

### A. PATIENT TRANSFERRED (complete for any change of modality, treating unit, sector and/or doctor)

Date of transfer:

<b>Current modality</b>	<input type="checkbox"/> Haemodialysis	<input type="checkbox"/> Peritoneal dialysis	<input type="checkbox"/> Transplant
<b>NEW modality</b>	<input type="checkbox"/> Haemodialysis	<input type="checkbox"/> Peritoneal dialysis	<input type="checkbox"/> Transplant

<b>Current Rx Unit</b>	
<b>NEW Rx Unit</b>	

<b>Current Sector</b>	<input type="checkbox"/> Public sector	<input type="checkbox"/> Private sector	<input type="checkbox"/> Public-Private Initiative
<b>NEW Sector</b>	<input type="checkbox"/> Public sector	<input type="checkbox"/> Private sector	<input type="checkbox"/> Public-Private Initiative

<b>Current Doctor</b>	
<b>NEW Doctor</b>	

### B. PATIENT STOPPED TREATMENT (complete for permanent end to treatment)

<b>Treatment stopped?</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<b>Date stopped:</b>
<b>Reason</b>	<input type="checkbox"/> Died	<input type="checkbox"/> Regained kidney function	<input type="checkbox"/> Doctor's recommendation
	<input type="checkbox"/> Lost to follow-up	<input type="checkbox"/> Left country	<input type="checkbox"/> Patient/family choice
	<input type="checkbox"/> Insufficient resources	<input type="checkbox"/> Other (give details)	
	<u>Details:</u>		

### C. PATIENT DIED

<b>Patient deceased?</b>	Yes <input type="checkbox"/>	<b>Date of death:</b>				
<b>Cause of death</b>	Cardiovascular <input type="checkbox"/>	Cerebrovascular <input type="checkbox"/>	Infection <input type="checkbox"/>	Malignancy <input type="checkbox"/>	Other <input type="checkbox"/>	Unknown <input type="checkbox"/>
	<u>Details:</u>					

## Definitions for the South African Renal Registry

**ESRD and Start Date of RRT** – ESRD refers to advanced CKD which is considered to be irreversible and which requires the initiation of renal replacement therapy (RRT). The start date is the date of first dialysis (for HD), the date of the first PD flushes or exchanges (for PD), or the date of pre-emptive transplantation (for TX without prior dialysis). For patients who are initially thought to have acute kidney injury (AKI) and are dialysed but who do not recover function and are then continued on chronic RRT, the start date is the date of the first dialysis, even though the diagnosis at that time was AKI and not ESRD.

**Initial RRT modality** – this is the intended first modality and should normally be the modality being used on day 91 of RRT. This means that someone who presents late and who is started on urgent HD but is soon established on PD will have PD recorded as the initial modality.

**Change in the responsible treating unit** – this refers to a change in the dialysis unit, PD follow-up unit/clinic, or transplant follow-up unit/centre/practice. A transfer entry in the Registry should not be done for short-term transfers to another unit when the intention is that the patient will return to the “home” unit e.g. holiday dialysis, temporary transfer to a unit with isolation facilities, etc.

**Hypertensive nephropathy or hypertensive renal disease** – this should be selected as the primary renal disease if there are documented episodes of malignant hypertension and there is no reason to suspect that the malignant hypertension is secondary to pre-existing renal disease (e.g. small kidneys, significant proteinuria). In the absence of malignant hypertension the following criteria should be met: hypertension known to precede renal dysfunction, left ventricular hypertrophy, proteinuria <1 g/day, and no evidence of other renal diseases. If there is still uncertainty then indicate the primary renal disease as “ESRD – cause unknown”.

**Lost-to-follow-up** – the Registry assumes that a functioning transplant is maintained unless there is evidence of a “transplant failure” or death. A dialysis modality is assumed to continue for only 365 days from the date of the last Registry entry, in the absence of evidence of death – thereafter the patient is considered lost-to-follow-up. Patients are also considered lost-to-follow-up 365 days after a “transplant failure” is recorded, if no further Registry entries exist.

**Recovered renal function** – these are patients who have been initiated on chronic HD/PD and who no longer require dialysis. The period of dialysis-free recovery must persist for at least 90 days.