

## Guide to RaDaR2 data entry for Idiopathic Nephrotic Syndrome (INS) patients

### Recruiting a patient to RaDaR – INS cohort

- RaDaR2 accessed via log in: <https://nww.radar.nhs.uk> (NHS computers only)  
For **technical support** relating to RaDaR please contact [nbn-tr.radar@nhs.net](mailto:nbn-tr.radar@nhs.net), or phone 0117 414 8158
- Go to the 'patients' tab and click 'Recruit patient'
- Enter the required details and click 'Search'
- Enter the patient's details manually if their record has not been found
- Select the appropriate Renal Unit and Cohort (diagnosis)
- Confirm the patient has been consented by selecting the 'Consent' check box

### For NephroS (Site Type A)

- Patient need to be additionally added to the NephroS cohort i.e. NephroS patients belong to both INS and NephroS cohorts.
- Go to Cohort tab, scroll down to select NephroS.
- 'From date' is the date of NephroS consent.

Cohorts

	Cohort	From Date	To Date	Recruited By	
	Idiopathic Nephrotic Syndrome	04/02/2016	-	Bristol Royal Hospital for Sick Children	
	NephroS	04/02/2016	-	Bristol Royal Hospital for Sick Children	

### For NURTuRE (NephroS – Site Type B)

#### New patients

- Patients need to be added into the NURTuRE-INS cohort (patients belong to 2 cohorts INS and NURTuRE-INS). This is important as this will bring up NURTuRE specific data entry tabs.

#### Existing NephroS patients (recruited pre-NURTuRE)

- If a patient consented to NephroS, and then has been resampled for NURTuRE, please use the date of NURTuRE sampling as the from date for NURTuRE-INS. (These patients will belong to 3 cohorts: INS, NephroS, NURTuRE-INS)

Cohorts

	Cohort ^	From Date	To Date	Recruited By	
	Idiopathic Nephrotic Syndrome	04/02/2016	-	Bristol Royal Hospital for Children	
	NURTuRE - INS	08/03/2017	-	Bristol Royal Hospital for Children	
	NephroS	04/02/2016	-	Bristol Royal Hospital for Children	

## All patients

### Patient View

- If the patient is already on Patient View (PV), their data will be auto populated
- If they are not on PV, contact your local Renal System Administrator and request that 'Send to PV flag is set' and that PV login details are sent out if required
- **This will save you a lot of manual data entry. Ideally patients should be added to PV before RaDaR online registration as this makes registration easier.**
  
- Anything with a red \* next to it, must be completed before the page can be saved.
- For all data entry, for each tab you need to click on the "New" button (generally top left hand corner)
- **Questions regarding data entry?** Please contact Liz Colby (NephroS Study Coordinator) – Liz.Colby@Bristol.ac.uk, 0117 331 3106.

### Study Specific Tabs

- Data entry for RaDaR-INS and NephroS is the same
- There are additional tabs for patients in NephroS-NURTuRE (Site-Type B)

<b>INS</b>	Primary Diagnosis	Genetics	Family History	Comorbidities	Pathology	Clinical Pictures	Lab Results	Medications	Relapses	Dialysis	Plasmapheresis	Kidney Transplants	Hospitalisations
<b>NephroS</b>													
<b>NURTuRE - INS</b>	Visits	Questionnaires	Socio-Economic	Other Family History	Diabetic Complications	Tube Samples							

## Index

	<b>Page #</b>
<b>Data Entry – Time Points</b>	4
<b>Demographics</b>	5
<b>Consultants</b>	5
<b>Hospitals</b>	5
<b>Primary Diagnosis</b>	6-7
<b>Genetics</b>	8
<b>Family History</b>	9
<b>Comorbidities</b>	10-12
<b>Pathology</b>	13
<b>Clinical Picture</b>	14
<b>Lab Results</b>	15-17
<b>Medications</b>	18-19
<b>Relapses</b>	20
<b>Dialysis</b>	21
<b>Plasmapheresis</b>	21
<b>Transplants</b>	22
<b>Hospitalisations</b>	23
<b>NURTuRE Specific Tabs (Site-Type B, NURTuRE sites only)</b>	24
<b>Samples</b>	24
<b>Questionnaires</b>	25-30

## **Data Entry – Time Points**

### **Absolute minimum at time of registration**

- Demographics – including patient address
- Primary diagnosis
- 

### **Baseline data to complete as soon after recruitment as possible (For NURTuRE this should be within 2 weeks of sample collection)**

- Consultants
- Genetics
- Family History
- Diagnosis
- Pathology (All reports available)
- Clinical picture (At diagnosis and recruitment)
- Results (for NURTuRE: to include all routine results collected at time of sample collection and retrospective eGFR (including: serum creatinine) and ACR (including urine creatinine and urine albumin)).
- Medications

### **For some patients:**

- Relapse
- Dialysis
- Plasmapheresis
- Transplants

### **For NURTuRE:**

Questionnaires (if applicable)

Samples – barcode and collection of bloods

### **Follow-Up data**

- **Prospectively: every 6 months from recruitment date**
- Update: Demographics, Primary diagnosis (if disease progression), Genetics, Family History, Diagnosis (extra renal features), Pathology
- Clinical picture
- Update Medication
- For some patients: Relapse, Dialysis, Plasmapheresis, Transplant
- **Retrospectively: every 6 months from date of diagnosis.**
- We appreciate that for some patients this will be a lot of data to backfill. Please concentrate on getting information at time of diagnosis and capturing information going forward from recruitment date. As time allows, focus on significant changes retrospectively with the ultimate aim of a clinical picture every 6 months from date of diagnosis.

## **Information required in each tab**

### **Demographics**

Please complete these fields:

- Name
- Date of Birth
- (Date of Death)
- Gender
- Ethnicity
- Patient #'s (NHS, Hospital...)
- Aliases (e.g. name changes)
- Address

### **Consultants**

Add patient's caring consultant by clicking on New.

If their consultant is not listed please email Fiona Braddon (fiona.braddon@nhs.net) with the consultants email address so they can be added.

### **Hospitals**

Add another hospital if patient is seen at DGH/ transferred to another hospital for treatment, this allows the other hospital to see and add information to the patient on RaDaR.

Please let the other hospital know of the patient transfer – especially if at times of treatment, biopsy or transplantation, when data and/or samples could be collected.

# Primary Diagnosis

Primary Diagnosis Idiopathic Nephrotic Syndrome

List View

Diagnosis*	# ^	Name	EDTA
<input type="text" value="Search"/>			
Select		SRNS - Primary Steroid Resistance	-
Select		SRNS - Secondary Steroid Resistance	-
Select		SRNS - Presumed Steroid Resistance	-
Select		SSNS - Partial Steroid Resistance	-
Select		SSNS - Steroid Sensitive	-
Select		SSNS - Steroid Dependant	-
Select		SSNS - Frequently Relapsing	-
Select		INS - Steroids NOT Tried	-

Choose the most specific diagnosis.  
[ERA-EDTA PRD codes](#)

Symptoms Date

Date of onset of symptoms.

Diagnosis Date\*

01/MM/YYYY if day is not known, 01/01/YYYY if only a year known.

To Date

Prenatal Diagnosis

Confirmed by Gene Test

Confirmed by Biochemistry

Confirmed by Clinical Picture

Confirmed by Biopsy

Comments

Select Primary Diagnosis from the list.  
**If diagnosis changes e.g. disease progression – please 1) Give the ‘old’ diagnosis end date and 2) Add a new diagnosis (rather than edit) so that no information is lost.**

**Confirmed by biopsy:** If select yes a further options tab will appear. Please select an option:  
- Minimal Change  
- FSGS  
- Mesangial Hypertrophy  
- Other (please state).  
(Nb. Please also complete pathology tab).

## Renal Disease Progression

View

Delete

Date of Onset of Renal Disease

DD/MM/YYYY

CKD 3A

DD/MM/YYYY

GFR = 45-59mL/min

CKD 3B

DD/MM/YYYY

GFR = 30-44mL/min

CKD 4

DD/MM/YYYY

GFR = 15-29mL/min

CKD 5

DD/MM/YYYY

GFR = <15mL/min

Date of ESRF

DD/MM/YYYY

Date of start of RRT

Save

Cancel

### **Renal Disease Progression**

If patient has not reached these CKD/ESRF stages then please leave boxes blank.

## Genetics

Please add all genetic reports available for the patient (e.g. karyotyping, NHS SRNS gene panel results.)

- Date Sample Sent
- Laboratory where sample was sent

**Karyotype:** XX, XY, not done, other  
(please state in summary box)

**Results:** please copy and paste  
genetic report findings into this box

### Genetics Idiopathic Nephrotic Syndrome

Date Sample Sent\*

Laboratory

Reference Number

Karyotype

Results

Summary



## Family History

### Family History Idiopathic Nephrotic Syndrome

**Parental Consanguinity\***  ▾

**Family History of Condition\***  ▾

**Other Family History**

---

**Relatives**

**Relationship\***  ▾

**RaDaR Patient ID**

---

**Parental Consanguinity:** Are the parents related to each other (Yes/No)

**Family History** – If you select yes. Then the relative's box below appears. If other family members have renal disease and are registered on the RaDaR database, please list their RaDaR number along with relationship.

**Other Family History:** Please mention family history of proteinuria, or of other syndromes.

## Comorbidities

This is for comorbidities, the patient's primary diagnosis should be included in the primary diagnosis tab.

- Add significant diagnoses and extra renal features with dates.
- Please use the list when possible, if not write in diagnosis text (e.g. ocular problems). There are two lists INS and ALL (see below).
- The important diagnoses to capture are listed below.
- Please note: You do not need to look through every page. Start typing in the "Diagnosis" box and it will search through the pre-populated list. If the term is not listed, use the free-text "Diagnosis Text" box (please use a diagnosis from the list where possible).

### Comorbidities

List View

Data Source\* Bristol Royal Hospital for Children

Diagnosis\* **INS** NURTuRE - INS All

#	Name	EDTA
	Alport Syndrome	-
	Atypical Haemolytic Uraemic Syndrome (AHUS)	-
	Asthma	-
	Sensorineural Deafness	-
	Deafness	-
	Dent disease	2629
	Developmental Delay	-
	Charcot Marie Tooth Disease	-
	Epilepsy	-
	Epileptic Encephalopathy	-

First Previous 1 2 3 Next Last

ERA-EDTA PRD codes.

Diagnosis Text\*   
Please use a diagnosis from the list where possible.

Status\*  Patient has this condition  
 Patient does NOT have this condition

Diagnosis Date\*   
Date of diagnosis.

To Date

Comments

There are two tabs:

**INS** – a list of the most important diagnoses to capture

**NURTuRE-INS** - conditions listed in the adult background questionnaire.

**All** – a comprehensive list of all comorbidities

### **Important diagnoses to capture**

#### **INS list (site-type A and B):**

- Alport Syndrome
- Atypical Haemolytic Uraemic Syndrome
- Asthma
- Bilateral Sesoryneural Deafness
- Deafness
- Dent Disease
- Developmental Delay
- Charcot Marie Tooth Disease
- Epilepsy
- Epileptic Encephalopathy
- Frasier Syndrome
- Gonadoblastoma
- Haematuria
- Learning Difficulty
- Lowe Syndrome
- Nail-Patella Syndrome
- Male Pseudohermaphroditism
- Mental Retardation Syndrome
- Microcephaly
- Microcoria
- Pierson Syndrome
- Thrombocytopenia

#### **NURTuRE-INS (Site Type B)**

[And these that are listed in the NURTuRE background questionnaire (page 3)]

- High blood pressure (Hypertension)
- Heart Attack (Myocardial Infarction)
- Heart balloon or stent treatment to open a narrowed artery (Angioplasty)
- Heart bypass operation (coronary artery bypass graft)
- Atrial fibrillation
- Heart failure
- Narrowing of arteries in your legs (Peripheral Vascular Disease)
- Stroke
- “Mini Stroke” (Transient Ischaemic Attack)
- Epilepsy
- Multiple Sclerosis
- Chronic Pain
- Parkinson’s disease
- Emphysema or COPD (Chronic Obstructive Pulmonary Disease)
- Asthma

- Cancer  
*If yes, what type(s)*
- Fractured bones  
*If yes, which bone(s)*
- Rheumatoid Arthritis
- Severe liver disease (Cirrhosis)
- Other liver disease (please describe)
- Severe Constipation
- Inflammatory Bowel Disease (Crohn's Disease or Ulcerative Colitis)
- Irritable Bowel Syndrome
- Stomach Ulcer or Duodenal Ulcer
- Hepatitis B
- HIV / AIDS
- Acute Kidney Injury
- Overactive thyroid gland
- Underactive thyroid gland
- Alcohol misuse
- Dementia
- Schizophrenia
- Depression

[Ladies only]

- In pregnancy:
  - Kidney Failure
  - High Blood Pressure
  - Protein in urine
  - Seizures

**What if no comorbidities to report?**

Only if there are no comorbidities to report – please add date and tick the no comorbidities box. This will score through all the diagnosis. If the patient later develops a condition, please add these details in. This will remove the line through the condition.

Comorbidities

Data Source\*

No comorbidities

Date\*

No results.

## **Pathology**

Include all biopsy reports (new entry for each separate procedure).

**Kidney Type** – Transplant or Native

**Image URL** – Please leave blank  
(NURTuRE - will be completed upon  
biopsy slides/block being sent to  
Birmingham)

**Histological Summary:** Please copy  
and paste full biopsy report  
including biopsy conclusion. **Please  
do not include any patient  
identifiers in the report.**

**Electron Microscopy (EM)** findings  
(normally given as a  
supplementary/additional report).  
Please copy and paste any  
additional reports.

## Pathology

List

View

Source\* Bristol Royal Hospital for Sick Children ▾

Date\*

Kidney Type

Kidney Side

Reference Number

Image URL

Histological Summary

## **Clinical Pictures**

- Follow-up ideally every 6 months from date of diagnosis or as patients attend for follow-up appointments. We appreciate that some patients may have years of follow-up data so there may be a delay in uploading this information.

In order of priority:

- 1) At time of diagnosis
- 2) At time of registration and 6-monthly going forward (or less frequently depending when patients are seen in clinic).

**Nb. We need a Clinical Picture (and lab results) completed for all dates when NephroS/NURTuRE blood (and urine for NURTuRE) are collected so we can correlate our research findings using the samples with the patient's clinical status.**

- 3) At significant times of acute illness prior to recruitment
- 4) 6 monthly from date of diagnosis to recruitment date (depending on data availability)

Yes/No responses to checklist.  
These are if these symptoms are present at the date of the clinic visit

In the comments box – copy and paste clinic letter (please include details of any relapses and response to medications given however please ensure this information is also captured on the 'Relapse' and 'Medication' tabs).

**Please remove any patient identifiers within the clinic letter e.g. replace names with an X.**

- Important Information to capture**
- Relapses, trigger for relapse, treatment given and response
  - Any changes to diagnosis, how progressing with disease, changes to medications
  - Any results from recent tests inc. biopsy
  - Dialysis, Plasma Exchange treatments
  - Are they listed for transplant?

### Clinical Pictures

List View

Date of Picture\*

Oedema

Hypovolaemia

Fever > 38°C

Thrombosis

Peritonitis

Pulmonary Oedema

Hypertension (Requiring Treatment)

Rash

Infection Necessitating Hospitalisation

Ophthalmoscopy

Comments



## Lab Results (Anthropomorphic, Blood and Urine)

To add a result, you must click 'New' in the top left hand corner. Then 'select' which result you want to input. You don't need to scroll through every page to find the result name - just start typing in the box below "available" and it will search from the list.

- Some results should auto-populate with Patient View Link. This will vary from local hospital so please find out what your local centre reports and manually input those that are not auto-populated (as a start, the measurements in bold are not routinely pulled across but there may be others so please check what your local procedures are).
- For NURTuRE sites, the following results **must be** reported at times of sampling (and should be done as routine bloods/urines as per SOP).

The screenshot shows the 'Lab Results' interface. At the top, there are 'List' and 'View' buttons. Below them are two tabs: 'INS' (which is highlighted in green) and 'All'. An arrow points from the 'INS' tab to a text box on the right. Below the tabs is a table with columns: Name, Short Name, Sample Type, Units, Min Value, and Max Value. The table is divided into 'Selected' and 'Available' sections. The 'Available' section has a search box and a list of tests, each with a 'Select' button. The tests listed are: Albumin (Alb, Blood, g/L, 10-60), Albumin : Creatinine Ratio (ACR, Urine, mg/mmol, 0.1-5000), Bacteria in Urine > 10<sup>5</sup>/ml (UBACT, Urine, -, -, -), C-Reactive Protein (CRP, Blood, mg/L, 0-501), and Calcium - Adjusted (AdjCa, Blood, mmol/L, 1-4.9). At the bottom, there is a pagination bar with buttons for 'First', 'Previous', '1', '2', '3', '4', '5', '6', '7', 'Next', and 'Last'.

### Two tabs:

**INS** – all results that need to be captured

**All** – comprehensive list of all bloods results that might be available.

## INS Specific Results

### Bloods

White Blood Cell Count	WBCs	10 <sup>9</sup> /L
Platelets	Plats	10 <sup>9</sup> /L
Hematocrit	HCT	L/L
Hb (Haemoglobin)	HB	g/L
Urea	Urea	mmol/L

### Retrospective Data (1):

Please add the last 5 scores of:

- eGFR
- Serum Creatinine
- Blood pressure
- Weight
- Height (children)

Sodium	Sodium	mmol/L
Potassium	Potassium	mmol/L
Estimated GFR	eGFR	ml/min/1.73m <sup>2</sup>
Serum Creatinine	Creatinine	µmol/L
Magnesium	Mg	mmol/L
<b>Corrected Calcium (or adjusted)</b>	<b>Ca_Corr (AdjCa)</b>	<b>mmol/l</b>
Phosphate	Phos	mmol/L
Serum Albumin	Alb	g/L
Bicarbonate	Bicarb	mmol/L
Uric acid	Urate	mmol/L
C-Reactive Protein	CRP	mg/L
Serum parathyroid hormone	PTH	pmol/L
Cholesterol	Cholest	mmol/L
HDL Cholesterol	hdl	mmol/L
LDL Cholesterol	ldl	mmol/L
Triglycerides	TG	mmol/L
Glucose (random)	Gluc	mmol/L

**If anaemic**

Ferritin	Ferr	µg/L = ng/ml
<b>Folate - Serum</b>	Folate	µg/L
Vitamin B12	VitB12	ng/L

**If diabetic**

HbA1c	HbA1c	mmol/mol
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**If on medication**

Tacrolimus	Tacro	ng/ml
Ciclosporin (Cyclosporine)	Ciclo	ng/ml

**Urine Dipstick**

<b>Glucose in urine</b>	<b>UDGLUC</b>	-
<b>Leucocytes in urine &gt;50</b>	<b>UDLEUC</b>	-
<b>Nitrites in urine</b>	<b>UDNIT</b>	-
<b>Haematuria</b>	<b>UDHAEM</b>	-
<b>Proteinuria</b>	<b>UDPROT</b>	-

<b>Urine Creatinine</b>	<b>UCREAT</b>	<b>mmol/l</b>
<b>Urine Albumin</b>	<b>Albuminuria</b>	<b>mcg/mg</b>
Urine Albumin to Creatinine ratio	ACR	mg/mmol

**Retrospective Data (2):**

Please add the last 5 scores of:

- Urine Creatinine
- Urine Albumin
- Urine ACR

And if available

- Urine protein
- Urine PCR

If also available (in addition to **ACR** for NURTuRE centres)

<b>Urine Protein</b>	<b>UPROT</b>	<b>g/L</b>
Urine Protein to Creatinine ratio	PCR	mg/mmol

### **Observations**

**Please ensure these are included for all visits where samples are taken (and 6 monthly if available).**

<b>Height</b>	<b>Height</b>	<b>cm</b>
Weight	Weight	kg
Diastolic Blood Pressure	BPdia	mmHg
Systolic Blood Pressure	BPsys	mmHg

## **Medications**

Please include medications since date of diagnosis. This should be auto-populated by PV (please check whether your local site sends across medications through PV) but if not, **a list of the most important medications to capture is on the next page. Please also capture medications taken during and after a relapse episode.**

You don't need to scroll through the list to find the drug name. Just start typing in the box below "Name" and it will search the list.

Please check that medications from Renal Systems and GP systems are recorded.

Dose text – can input details on weaning regime here

Route: Oral, Intravenous, Intramuscular, Subcutaneous, Per Rectum, Topical, Patch

### Medications

Data Source\*

Drug	Name ^	Group
<input type="button" value="Select"/>	Antihypertensive - Angiotensin II Receptor Antagonist	Antihypertensive
<input type="button" value="Select"/>	Antihypertensive - Beta Blockers	Antihypertensive
<input type="button" value="Select"/>	Antihypertensive - Calcium Channel Blockers	Antihypertensive
<input type="button" value="Select"/>	Aranesp	ESA (EPO)
<input type="button" value="Select"/>	Aspirin	Anticoagulant
<input type="button" value="Select"/>	Atenolol	Antihypertensive - Beta Blockers
<input type="button" value="Select"/>	Atorvastatin	Statins
<input type="button" value="Select"/>	Azathioprine	Immunosuppressive
<input type="button" value="Select"/>	Basiliximab	Immunosuppressive
<input type="button" value="Select"/>	Bendroflumethiazide	Diuretics

First Previous 1 2 3 4 5 6 ... 12 13 Next Last

Drug Text   
Please use a drug from the list where possible.

From Date\*

To Date

Dose Quantity

Dose Unit

Dose Text  →  
Please use dose quantity and dose unit for new medications.

Frequency

Route  →

**Most important drugs to capture in 'Medications' tab:**

**Immunosuppressives**

- Methyl Prednisolone
- Prednisolone
- Ciclosporin
- Tacrolimus
- Mycophenolate Mofetil - MMF
- Corticosteroids
- Cyclophosphamide
- Alemtuzumab
- Azathioprine
- Basiliximab
- Daclizumab
- Eculizumab
- Rituximab
- Sirolimus

Please only use the general 'Immunosuppressive' choice, if no details about the actual drug given can be found.

**Anti-hypertensives (especially ACE inhibitors (ACEi) and Angiotensin receptor blockers (ARBs))**

- Lisinopril
- Captopril
- Enalapril
- Ramipril
- Irbesartan
- Losartan
- Candesartan Cilexetil
- Olmesartan
- Eprosarten
- Telmistaartan
- Valsartan

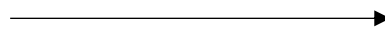
These are more general terms used in the table: Antihypertensive, Antihypertensive - ACE Inhibitor, Antihypertensive - Angiotensin II Receptor Antagonist. Please use specific drug name if at all possible. Use these only if filling in retrospective data where it is unknown which drug was used.

**Other**

- Albumin IV infusion
- Levamisole

## Relapses

**NephroS and NURTuRE patients: Please take relapse blood samples at these episodes.**



**Kidney Type:** Transplant, Native



**Remission Type:** Complete, Partial,  
None

## Relapses

List View

Date of Relapse\*

Kidney Type\*

Viral Trigger

Immunisation Trigger

Other Trigger

### Drugs Given for Relapse

High Dose Oral Prednisolone

IV Methyl Prednisolone

### Remission

Date of Remission

Remission Type

#### Definition of remission:

- **Full remission: Trace or negative urinary protein on dipstick or urine protein:creatinine ratio <20mg/mmol within 6 months of commencing therapy**
- **Partial Remission: Urinary protein 1+ or more (or urine protein:creatinine ratio >20mg/mmol) but serum albumin >25 within 6 months of commencing therapy**



## Dialysis

### Dialysis

List View

Source\* Bristol Royal Hospital for Sick Children

Modality\*

From Date\*

To Date

Save Cancel

#### Modality (choose from):

Haemodialysis  
Haemofiltration  
Haemodiafiltration  
Ultrafiltration  
CAPD  
Assisted CAPD  
APD  
Assisted APD  
Peritoneal Dialysis – Type unknown  
Hybrid CAPD with HD  
Hybrid APD with HD  
Hybrid APD with CAPD

## Plasmapheresis

### Plasmapheresis

List View

Source\* Bristol Royal Hospital for Sick Children

From Date\*

To Date

No. of Exchanges

Response

Save Cancel

#### Modality:

Live - Sibling  
Live – Father  
Live – Mother  
Live – Child  
Live – Other Relative  
Live – Genetically unrelated  
Live – With transplant of other organ  
Live – non UK  
Cadaver  
Cadaver – With transplant of other organ  
Non-heart beating  
Unknown

## Transplants

## Transplants

**Source\***

**Date\***

**Transplant Hospital**

**Modality\***

**Date of Recurrence**

**Date of Failure**

---

**Rejections**

**Date of Rejection\***

---

---

**Biopsies**

**Date of Biopsy\***

**Recurrence of Disease**

---

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## Hospitalisations

Any renal hospitalisations are likely to be covered in the other RaDaR/INS tabs. However, if there is any renal related hospital admissions that aren't covered please include here.

## Hospitalisations

---

**Source\***

**Date of Admission\***

**Date of Discharge**

**Reason for Admission\***

**Comments**

**NURTuRE-INS Additional Data Input (see NURTuRE-INS tab)**

Additional NURTuRE tabs. These appear when patient added into NURTuRE-INS cohort (via cohort tab).

**For children** – please complete samples and questionnaires (depending on age – see below)

**For adults** – please complete all tabs (although see below for which questionnaires are relevant)

## Tube Samples

### Samples

List View

Date\*

Barcode\*

Protocol\*

Visit\*

**Protocol:**  
 Adult  
 Children >30kg  
 Children 15-30kg  
 Children <15kg

**Visit:**  
 Baseline/Disease  
 Follow-Up  
 2<sup>nd</sup> Visit (children only)

**Barcode** – 5 digit barcode e.g. 80000 NOT RaDaR number



- If all samples in the SOP have been collected, this will auto-populate. **Only if there have been problems during sample collection and the intended number of aliquots have not been collected, would this be changed. The reason why these were not collected must be documented.**
- Please note, the majority of the sample information/ barcodes/ which box etc will be recorded on the separate barcode tracking software.
- Having this information on RaDaR allows a quick overview of what has been banked and can feed into clinical data.

## **Questionnaires**

To be completed on paper and inputted by the Research Team. Please keep the paper copy of questionnaire in your local site-file.

The tabs reflect the format of the paper questionnaires.

Questionnaires NURTURE - INS



### **Adults**

- EQ-5D-5L
- HADS
- IPOS
- 6CIT

### **Children >= 7 years only (child completed)**

- CHU9D
- 5Q-5D-Y

### **Background Questionnaire (Adults).**

See below for each page of the questionnaire and where each piece of information needs to be inputted (there is no separate background questionnaire tab).

From this questionnaire, information for the the following tabs can be completed:

- Socio Economic
- Comorbidities
- Family History and Other Family History
- Diabetic Complications
- Visits
- Medication

**Background Questionnaire (Adults): Page 1**

Add/Check against the **Demographics Tab**

**NephroS Background Information Form**

RADAR No  Date of visit  Visit Year  Baseline   
 Follow-Up

Please complete each of the questions below. If you are uncertain, leave the section blank and we will help you complete it at your study visit.

**Date of Birth**

**Gender**

**Your Ethnicity—please tick one**

<input type="checkbox"/>	White - British
<input type="checkbox"/>	White - Irish
<input type="checkbox"/>	Other White background
<input type="checkbox"/>	Mixed - White and Black Caribbean
<input type="checkbox"/>	Mixed - White and Black African
<input type="checkbox"/>	Mixed - White and Asian
<input type="checkbox"/>	Other Mixed background
<input type="checkbox"/>	Asian or Asian British - Indian
<input type="checkbox"/>	Asian or Asian British - Pakistani
<input type="checkbox"/>	Asian or Asian British - Bangladeshi
<input type="checkbox"/>	Other Asian background
<input type="checkbox"/>	Black Caribbean
<input type="checkbox"/>	Black African
<input type="checkbox"/>	Other Black background
<input type="checkbox"/>	Chinese
<input type="checkbox"/>	Other ethnic background
<input type="checkbox"/>	Do not wish to say

**Your Educational qualifications—**

*just tick highest level achieved*

<input type="checkbox"/>	None
<input type="checkbox"/>	GCSE (or equivalent)
<input type="checkbox"/>	A Levels
<input type="checkbox"/>	NVQ Level 1-3
<input type="checkbox"/>	NVQ Level 4-5
<input type="checkbox"/>	First degree
<input type="checkbox"/>	Higher degree

**Your Employment Status**

<input type="checkbox"/>	Working full time
<input type="checkbox"/>	Working Part time
<input type="checkbox"/>	Retired
<input type="checkbox"/>	Student
<input type="checkbox"/>	Long term sick/ disabled
<input type="checkbox"/>	Looking after family at home
<input type="checkbox"/>	Unemployed
<input type="checkbox"/>	Not in work for other reason

**Marital status**

<input type="checkbox"/>	Single
<input type="checkbox"/>	Married/Civil Partner
<input type="checkbox"/>	Divorced/Civil Partnership dissolved
<input type="checkbox"/>	Widowed/Surviving Civil Partner
<input type="checkbox"/>	Separated
<input type="checkbox"/>	Do not wish to disclose

**What is your first language ?**

English  Other

**Please rate your fluency in English**

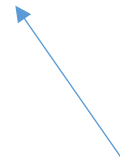
<input type="checkbox"/>	Unable to speak or read
<input type="checkbox"/>	Very weak fluency
<input type="checkbox"/>	Moderate fluency
<input type="checkbox"/>	Good fluency

**How often do you need to have someone help you when you read?**

<input type="checkbox"/>	Never
<input type="checkbox"/>	Rarely
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Often
<input type="checkbox"/>	Always

Insert into the **Socio-Economics Tab**





Insert into the **Socio-Economics** Tab

Insert into **Family History** Tab (please input data even if 'no')

Insert into **Other Family History** Tab (please input data even if 'no')

<p><b>Smoking</b></p> <p>Do you currently smoke cigarettes? YES / NO</p> <p><i>If Yes</i></p> <p>For how many years have you smoked ? <input type="text"/></p> <p>How many cigarettes do you smoke per day <input type="text"/></p> <p>Have you ever tried to stop smoking ? YES / NO</p> <p>Have you previously smoked cigarettes YES / NO</p> <p><i>If Yes</i></p> <p>For how many years did you smoke ? <input type="text"/></p> <p>How many cigarettes did you smoke per day ? <input type="text"/></p> <p>When did you stop smoking ? <input type="text"/> Year</p>	<p><b>Do you drink alcohol? YES / NO</b></p> <p><i>If Yes</i></p> <p>How many of the following do you have per week:</p> <p>Pints of beer <input type="text"/></p> <p>Pints of cider <input type="text"/></p> <p>Glasses of red wine <input type="text"/></p> <p>Glasses of white wine <input type="text"/></p> <p>Tots of spirits <input type="text"/></p> <p>Cocktails or other drinks <input type="text"/></p>												
<p>Please indicate what type of diet you follow</p> <table border="1"><tr><td><input type="checkbox"/></td><td>Normal mixed</td></tr><tr><td><input type="checkbox"/></td><td>Vegetarian eat fish</td></tr><tr><td><input type="checkbox"/></td><td>Vegetarian</td></tr><tr><td><input type="checkbox"/></td><td>Vegan</td></tr><tr><td><input type="checkbox"/></td><td>Low Protein</td></tr><tr><td><input type="checkbox"/></td><td>Other - specify - <input type="text"/></td></tr></table>		<input type="checkbox"/>	Normal mixed	<input type="checkbox"/>	Vegetarian eat fish	<input type="checkbox"/>	Vegetarian	<input type="checkbox"/>	Vegan	<input type="checkbox"/>	Low Protein	<input type="checkbox"/>	Other - specify - <input type="text"/>
<input type="checkbox"/>	Normal mixed												
<input type="checkbox"/>	Vegetarian eat fish												
<input type="checkbox"/>	Vegetarian												
<input type="checkbox"/>	Vegan												
<input type="checkbox"/>	Low Protein												
<input type="checkbox"/>	Other - specify - <input type="text"/>												
<p>Do you have a close relative who also has Nephrotic Syndrome or history of proteinuria? YES / NO</p> <p><i>If "YES" please circle which</i></p>													





**Background Questionnaire (Adults): Page 3**

**Diabetes** If you have diabetes is this Type 1 or Type 2 (please circle)

Do you also have diabetic eye problems (retinopathy)? YES / NO

Have you had laser treatment on your eye YES / NO

Do you have nerve problems (diabetic neuropathy)? (please circle) YES / NO

Have you ever had foot ulcers?  
NO, never / YES, previously but now healed / YES, ongoing problem

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**Are you currently or have you previously been affected by any of the following -**  
(please tick if yes and give date first diagnosed or date of the event)

High blood pressure (Hypertension)

Heart Attack (Myocardial Infarction)

Heart balloon or stent treatment to open a narrowed artery (Angioplasty)

Heart bypass operation (coronary artery bypass graft)

Atrial fibrillation

Heart failure

Narrowing of arteries in your legs (Peripheral Vascular Disease)

Stroke

"Mini Stroke" (Transient Ischaemic Attack)

Epilepsy

Multiple Sclerosis

Chronic Pain

Parkinson's disease

Emphysema or COPD (Chronic Obstructive Pulmonary Disease)

Asthma

Cancer  
if yes, what type(s)

Fractured bones  
if yes, which bone(s)

Rheumatoid Arthritis

Severe liver disease (Cirrhosis)

Other liver disease (please describe)

Severe Constipation

Inflammatory Bowel Disease (Crohn's Disease or Ulcerative Colitis)

Irritable Bowel Syndrome

Stomach Ulcer or Duodenal Ulcer

Hepatitis B

HIV / AIDS

Acute Kidney Injury

Overactive thyroid gland

Underactive thyroid gland

Alcohol misuse

Dementia

Schizophrenia

Depression

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**Ladies only:** Have you previously been pregnant? YES / NO

If "yes", were you affected by any of the following during any pregnancy

Kidney Failure	High Blood Pressure
Protein in your urine	Seizures

If patient has diabetes, please insert into **diabetic complications** tab

Insert into **comorbidities** tab (see below for how each comorbidity is coded for)

**Table of how each comorbidity listed above is coded for in RaDaR**

<b>Questionnaire</b>	<b>Coded in RaDaR</b>
High blood pressure (Hypertension)	Hypertension
Heart Attack (Myocardial Infarction)	Myocardial Infarction Myocardial Infarction NSTEMI Myocardial Infarction STEMI
Heart balloon or stent treatment to open a narrowed artery (Angioplasty)	Angioplasty
Heart bypass operation (coronary artery bypass graft)	CABG – Coronary Artery Bypass Graft
Atrial fibrillation	Atrial fibrillation
Heart failure	Cardiac Failure
Narrowing of arteries in your legs (Peripheral Vascular Disease)	Peripheral Vascular Disease PVD Endarterectomy (for peripheral revascularisation) Bypass Graft (for peripheral revascularisation)
Stroke	Stroke CVA Stroke – Cerebral Infarct Stroke – Intracerebral haemorrhage Stroke – Unknown type
“Mini Stroke” (Transient Ischaemic Attack)	Transient Ischaemic Attack TIA
Epilepsy	Epilepsy
Multiple Sclerosis	Multiple Sclerosis
Chronic Pain	Pain – chronic
Parkinson’s disease	Parkinsons disease
Emphysema or COPD (Chronic Obstructive Pulmonary Disease)	COPD
Asthma	Asthma
Cancer <i>If yes, what type(s)</i>	Cancer – (type) Metastases
Fractured bones <i>If yes, which bone(s)</i>	Fracture – (type)
Rheumatoid Arthritis	Rheumatoid Arthritis
Severe liver disease (Cirrhosis)	Cirrhosis of Liver
Other liver disease (please describe)	Liver Disease not <b>cirrhosis</b>
Severe Constipation	Constipation - severe
Inflammatory Bowel Disease (Crohn’s Disease or Ulcerative Colitis)	IBD – Inflammatory Bowel Disease
Irritable Bowel Syndrome	IBS - Irritable Bowel Syndrome
Stomach Ulcer or Duodenal Ulcer	Gastric Ulcer Duodenal Ulcer Peptic Ulcer
Hepatitis B	Hepatitis B Hepatitis B - Chronic
HIV / AIDS	HIV / AIDS
Overactive thyroid gland	Hyperparathyroidism
Underactive thyroid gland	Hypothyroidism
Alcohol misuse	Alcohol Abuse – Current Alcohol Abuse - Past
Dementia	Dementia
Schizophrenia	Schizophrenia
Depression	Depression
<u>Ladies during pregnancy:</u> Kidney Failure	Renal failure in pregnancy

High Blood Pressure Protein in Urine Seizures	Hypertension in Pregnancy Proteinuria in pregnancy Seizures in pregnancy
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**Additional co-morbidities to note:**

- AKI
- Amputation:
  - Arm
  - Leg above knee
  - Leg below knee

**Background Questionnaire (Adults): Page 4**

**Vaccinations** - Have you previously been vaccinated against:

Flu (influenza)	YES / NO	Pneumonia (pneumococcus)	YES / NO
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Have you been admitted to hospital in the past year? YES / NO

If "yes" how many admissions in the past year

How many of these admissions were an Emergency  and how many planned

How many days in total have you spent in hospital in the past year?

In how many admissions were you given antibiotics?

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Do you regularly take any of the following pain medications ?

	No	Yes	Number of tablets per	Number of years
Paraetamol	<input style="width: 20px;" type="text"/>	<input style="width: 20px;" type="text"/>	<input style="width: 40px;" type="text"/>	<input style="width: 40px;" type="text"/>
Co-codamol	<input style="width: 20px;" type="text"/>	<input style="width: 20px;" type="text"/>	<input style="width: 40px;" type="text"/>	<input style="width: 40px;" type="text"/>
Ibuprofen (e.g Brufen / Nurofen)	<input style="width: 20px;" type="text"/>	<input style="width: 20px;" type="text"/>	<input style="width: 40px;" type="text"/>	<input style="width: 40px;" type="text"/>

← Insert into **Visits** tab

**Your Medication** - Please write the names and doses of **all** the medication you are currently taking. Include Herbal remedies. You can just attach your last repeat prescription sheet.

Name	Dose	Times per day

← Insert into **Medications** tab

