

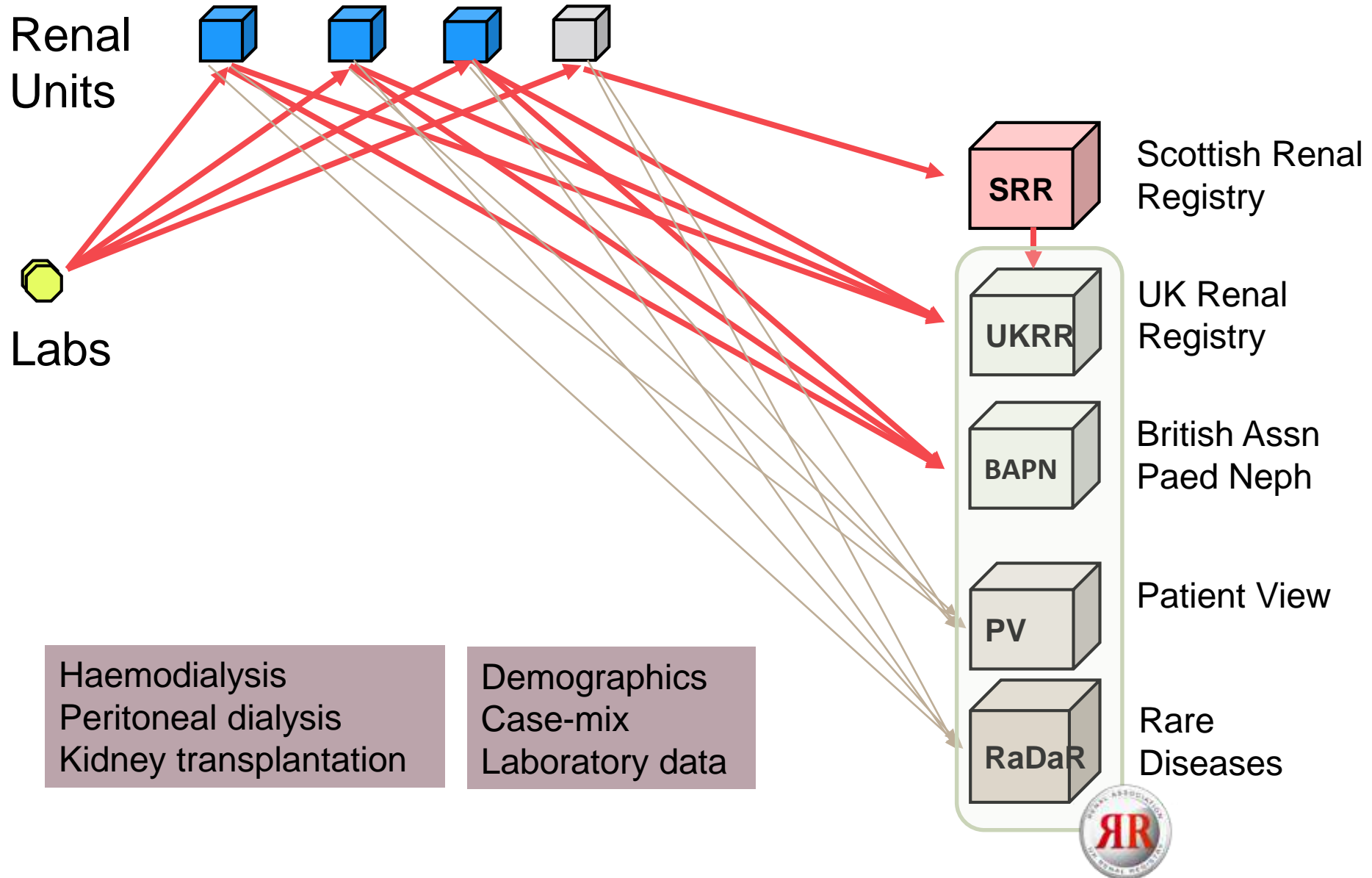


Renal Registry and RaDaR

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Medical Director of the UK Renal Registry

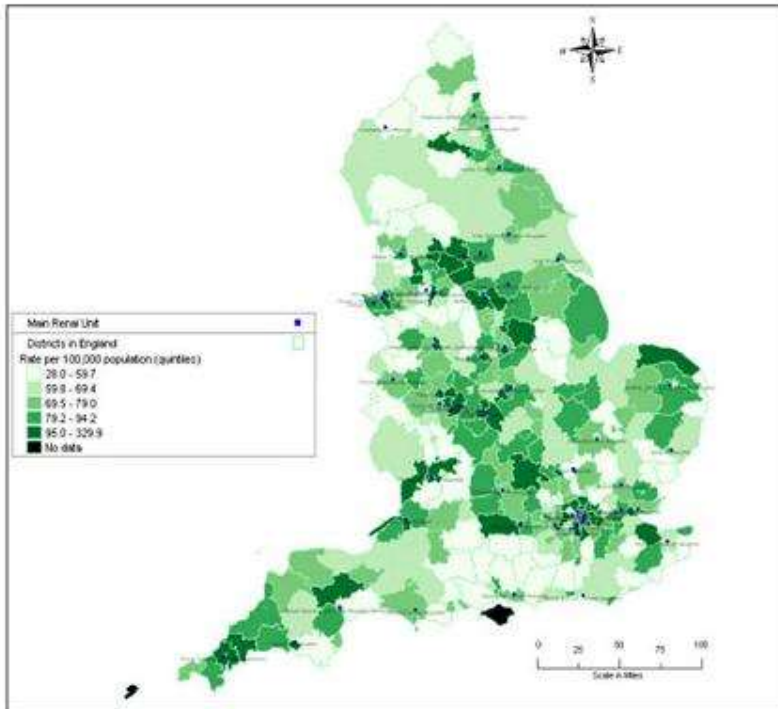
ADPKD Information Day, Bristol, March 2017

Data capture

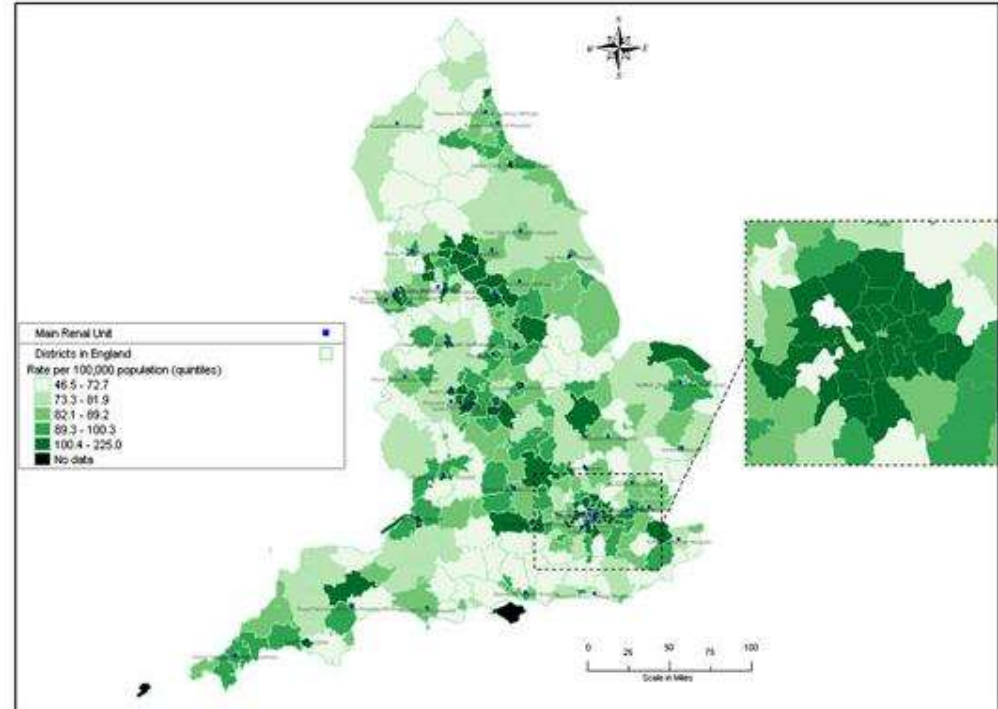


Equity of access to treatment

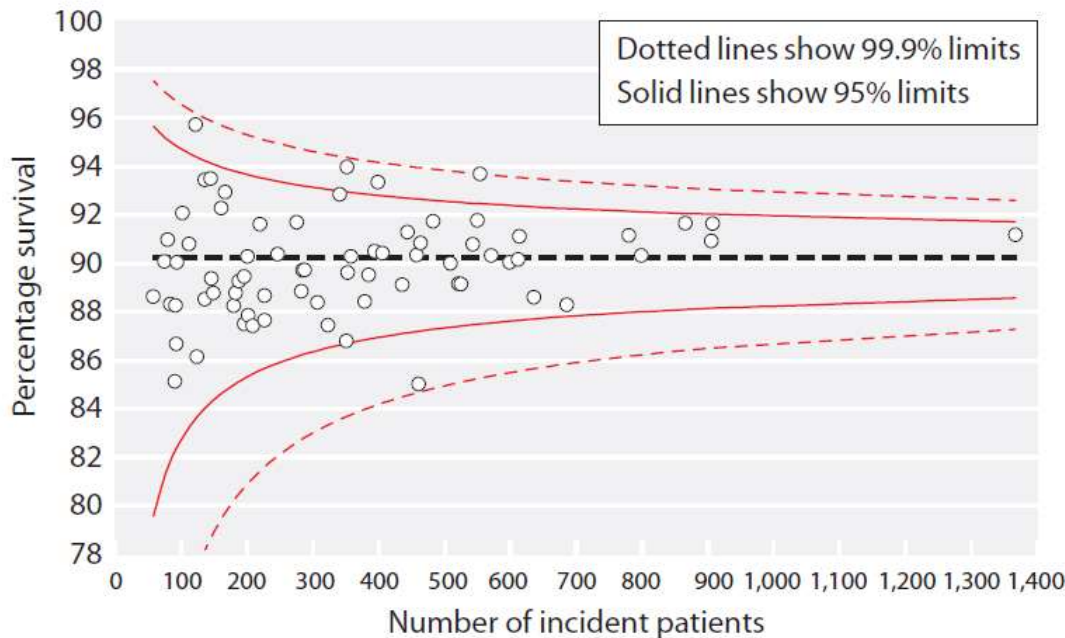
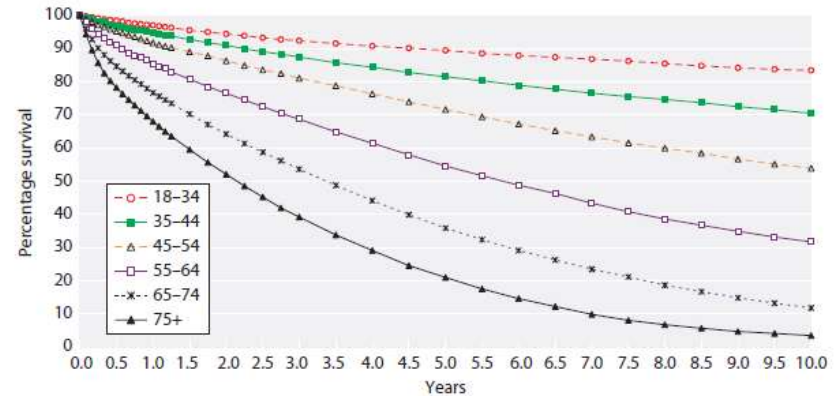
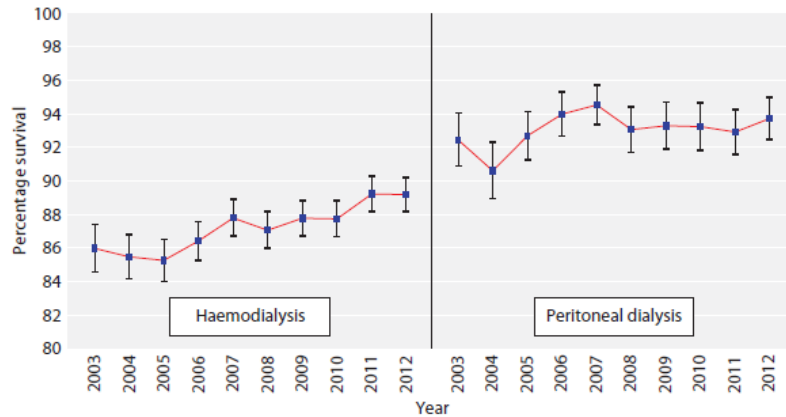
Model 1: Null



Model 3: Socio-demographic + Renal service



Survival



- Improving survival over time
- Information for decision making
- Quality assurance

Infection data

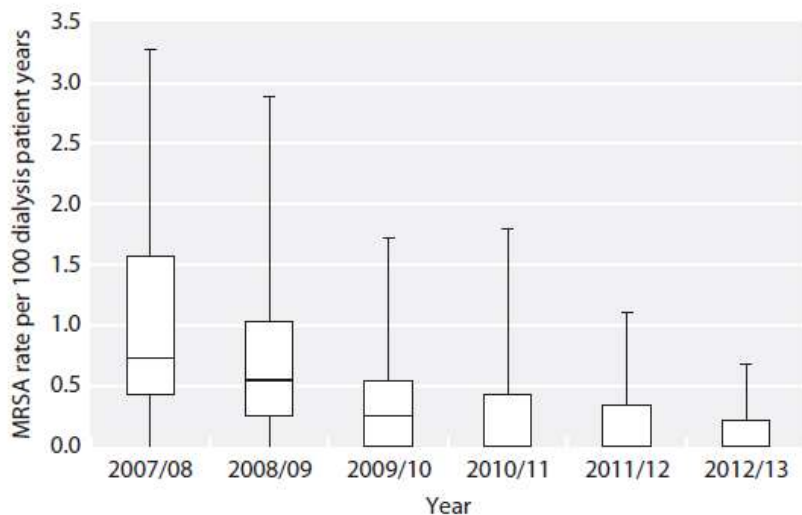


Fig. 12.1. Box and whisker plot of renal centres' MRSA rates per 100 dialysis patient years by reporting year

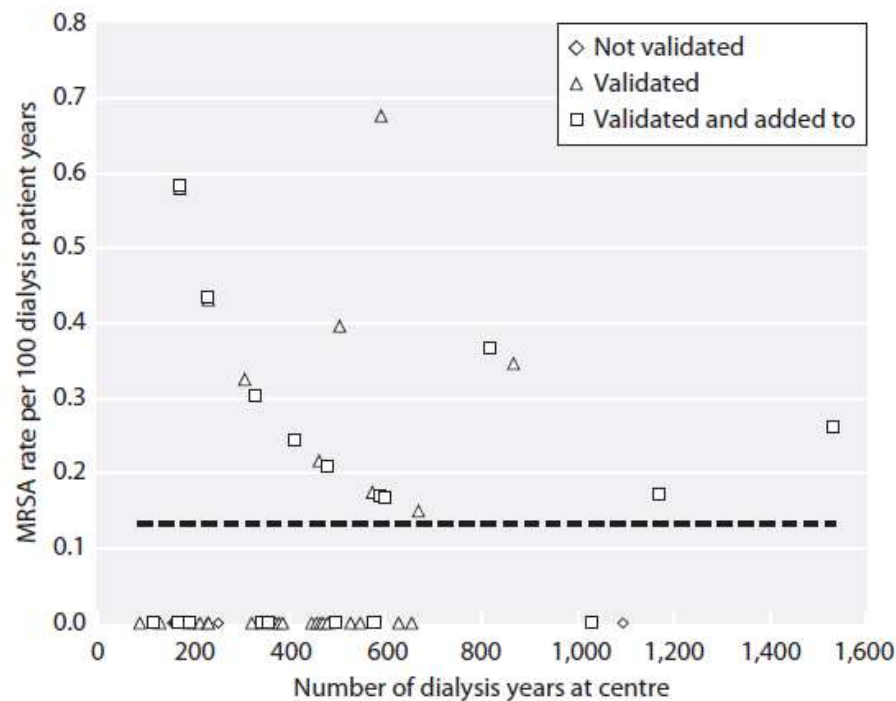


Fig. 12.2. Funnel plot of the MRSA bacteraemia rate per 100 dialysis patient years by renal centre, 1st May 2012 to 30th April 2013
Dotted line depicts rate for whole cohort



Summary of access to transplantation

Access to	Increasing social deprivation	Ethnicity		
		South Asians	Blacks	Whites
Transplant (any type)	↓	↓	↓	Reference
Deceased donor waiting list	↓	→	→	Reference
Deceased donor transplant once listed	→	↓	↓	Reference
Live donor transplant	↓	↓	↓	Reference
Pre-emptive transplant	↓	↓	↓	Reference
Extended criteria donor kidneys	↑	→	→	Reference

SIMPLIFIED

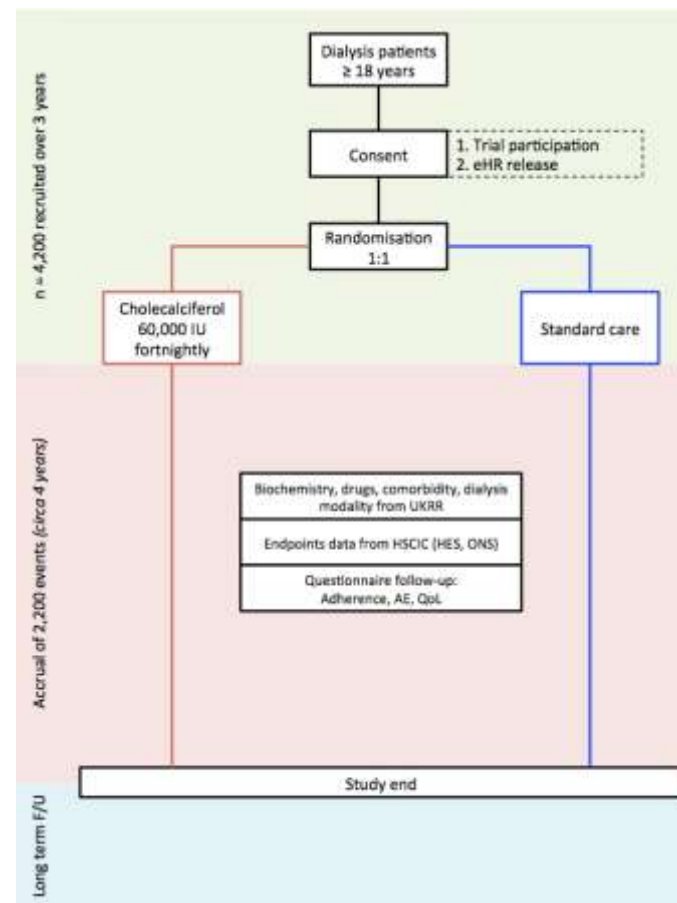


Registry trial

- NIHR HTA, Dr Hiemstra, Cambridge
- **Vitamin D** in HD & PD patients (n=4,200).
- One tablet per fortnight
- Does it reduce **all-cause mortality**

- Recruitment over 3 years
- Follow up ~ 7 years (2,200 events)
- UKRR providing long term follow up through the Registry.

**RECRUITMENT STARTS
MARCH 2017**



RaDaR

Rare Disease Registry

Background

- RaDaR began in 2009, recruiting paediatric patients with Steroid Resistant Nephrotic Syndrome (SRNS) and Membranoproliferative Glomerulonephritis (MPGN).
- In 2012 it expanded to other conditions in paediatric centres and then to adult centres in Autumn 2013.
- RaDaR is managed by a series of Rare Disease Groups consisting of experts in each condition.

Recruits by Rare Disease Group

On 1st March 2017:

- 10,831 UK patients in RaDaR
- From 79 Renal Units

Rare Disease Group	Current data entry		
	Generic	Specific	Recruits
ADPKD	√	√	2170
ADTKD/FUAN	√	√	94
aHUS	√		115
Alport Syndrome	√	√	407
APRT-D	√		6
ARPKD	√	√	125
Calciophylaxis	√	In Progress	19
Cystinosis	√		96
Cystinuria	√		292
Dent Disease & Lowe Syndrome	√	In Progress	44
Fabry Disease	√		8
Fibromuscular Dysplasia	√		7
HNF1-B	√	√	42
Stec HUS	√		84
Hyperoxaluria	√		77
Hypokalaemic Alkaloses	√	√	201
IgA Nephropathy	√	In Progress	1285
MPGN, Dense Deposit Disease and C3 Glomerulopathy	√	√	577
Membranous Nephropathy	√		1187
Nephrotic Syndrome	√	√	1756
Pregnancy & Chronic Kidney Disease	√	√	244
Pure Red Cell Aplasia	√		2
Retroperitoneal Fibrosis	√		50
Tuberous Sclerosis	√		34
Vasculitis	√		1943

Data Capture

Primary Diagnosis Membranoproliferative Glomerulonephritis / Dense Deposit Disease

Edit

Source RaDaR (RADAR)

Diagnosis Membranoproliferative Glomerulonephritis / Dense Deposit Disease

Symptoms Date -

From Date 21/11/2013 (66 years)

To Date -

Confirmed by Gene Test ?

Confirmed by Biochemistry ?

Confirmed by Clinical Picture ?

Confirmed by Biopsy ✓

Biopsy Diagnosis -

Comments This is a dummy patient

Patient benefits of joining RaDaR

- Access to your clinical data online via Patient View
- Ability to be contacted about potential research studies or patient information events
- Contribute to the increase in knowledge about your condition

Contact Details

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- RaDaR - <https://nww.radar.nhs.uk> - patient registry for professional access via NHS computers
- RareRenal - www.rarerenal.org - public information about rare kidney diseases
- PatientView - www.patientview.org patient accessible health records



Where can I find out more?!

