

# CHILDREN'S RENAL UNIT

Annual report 2010-11

Bristol Royal Hospital for Children



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**Photo front cover: 6 year old boy enjoying Disneyland with his sister, supported by the charity “Make- a- wish”. (With kind permission from parents)**

# 1 SUMMARY

- Increase in Southwest patient workload sustained over the past 5 years
- Sustained increase in bed-days for the 0-6 year olds which account for over 50% of total bed-days compared to 20-30% prior to 2006
- Persistent high use of plasma exchange since 2009 with double the use compared to 2008-9. Predominantly due to increase in patients with atypical haemolytic uraemic syndrome
- Stable transplant rate compared with recent years. **Fifteen transplants between April 2010-11**
- **23.7 % of children with ESRF on dialysis** ( cf national statistics 24% of children < 15 years with ESRF on dialysis)

## 2 INTRODUCTION

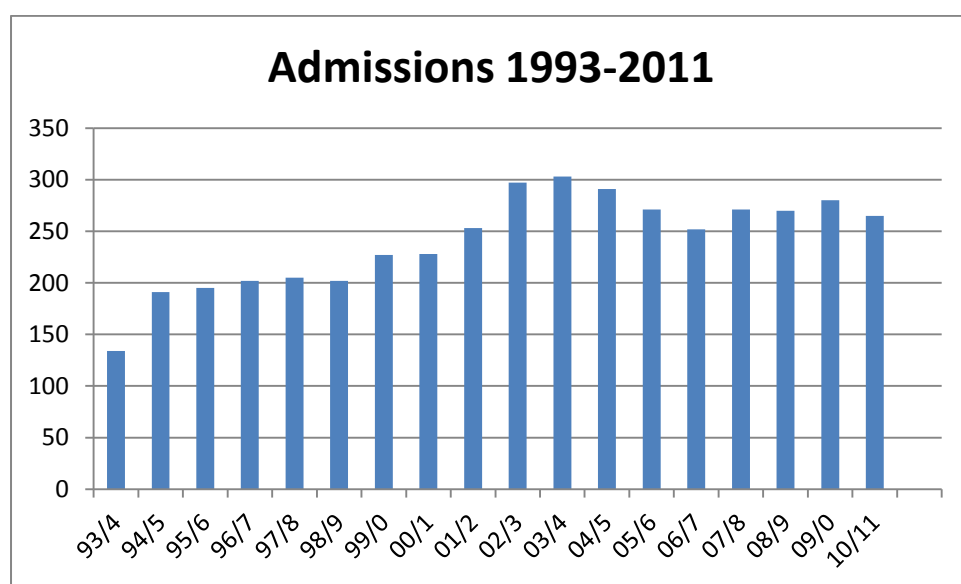
The Bristol based Children's Renal Unit provides a comprehensive nephrology services for the South and West of England, covering a population of over four million. It is one of ten children's renal units within the UK offering a fully comprehensive service; three further units offer dialysis but not transplantation. Between 2002 and 2006 the Cardiff Unit was unable to offer an inpatient service due to a staffing crisis and all inpatient care was transferred to Bristol. Cardiff reopened to inpatients in 2006 but transplantation for South and West Wales remains in Bristol increasing the Bristol transplantation base population to over 6 million. The neighbouring units are sited in Birmingham and London.

The Southwest service was started in 1976. The service now has the support of a full multi-disciplinary team, which includes trained paediatric renal nurses, community renal nurses, a full time social worker, two part-time children's renal dieticians, specialist pharmacy support, play specialists, schoolteachers and a clinical psychologist.

In April 2001 the service moved from Southmead Hospital to the purpose built children's hospital, the Bristol Royal Hospital for Children. The unit has 9 inpatient beds. There is a 4-bedded haemodialysis unit and one extra bed for plasma exchange. The proximity to the other children's specialty services has again proved invaluable this year.

This report details the inpatient activity of the Children's Renal Unit for the April 2010 to end March 2011. This is the SEVENTEENTH annual report and the NINTH report from the Bristol Royal Hospital for Children. Where appropriate, activity has been compared with the previous year's activity. From 2003-2006 data has been reported in relation to the patient's SHA. In previous years data was reported in relation to patients' District Health Authorities (DHA). As there is no direct comparison with previous years some of the data relating to DHAs has been reported for previous years. For 2006-2011 data have been allocated to the Primary care trust configurations.

Although it appears that there has been a stabilization of admissions over the past few years the workload from the Southwest region has increased since 2006. From 2006-11 there has been a reduction in workload from Wales but the increase in the SW work has resulted in no significant overall reduction in workload. The renal unit has also managed as many children as possible without admission with the support of the Community team



## 3 PERSONNEL

### CLINICAL TEAM

|  |   |
|--|---|
| Consultant Paediatric Nephrologist     | Dr Mary E McGraw  |
| Consultant Paediatric Nephrologist     | Dr E Jane Tizard  |
| Professor of Paediatric Renal Medicine | Professor Moin Saleem   |
| Consultant Paediatric Nephrologist     | Dr Jan Dudley   |
| Consultant Paediatric Nephrologist     | Dr Carol Inward   |
| Consultant Paediatric Nephrologist     | Dr Richard Coward *   |
| Staff Grade Paediatric Nephrology      | Dr Ezzat Afifi (moved 2010)   |
| Consultant Paediatric Urologist        | Mr Guy Nicholls   |
| Consultant Paediatric Urologist        | Mr Mark Woodward  |
| Ward Sister                            | Claire Hamblyn  |
| Charge nurse                           | Dan Speakman  |
| Haemodialysis Sister                   | Daniela Munn  |
| Community Renal Nurses                 | Jo Woodland (Sister), Anne Johnston, Elizabeth Griffiths  |
| Social Worker                          | Susannah Gibb   |
| Dieticians                             | Sarah Trace, Laura James  |
| Play Specialists                       | Sally Tutton and Shirley Thomas   |
| Pharmacist                             | Jenny Haylor/ Rebekah Devonald Morris   |
| Clinical psychologists                 | Sue Dolby, Dr Cara Davis  |
| Transplant surgeons                    | Mr Paul Lear, Mr Barry Pentlow, Mr David Mitchell, Mr Justin Morgan, Mr Najib Kadi Mr Bill Neary Mr A Weale |
| Transplant co-ordinators               | Diane Evans, Kay Hamilton, Tracey Fleming, Shirley Dowle and Jo Metcalfe                                    |
| Management Team                        | Jacqueline Cornish, Rebecca Dunn, Ian Barrington  |

### CONTACT NUMBERS

#### CONSULTANTS

The consultants carry pagers and/or mobile telephones, and there is always at least one consultant available to provide advice. To contact phone 0117 9230000 (Hospital switchboard) and ask for consultant paediatric nephrologist on call.

#### CONSULTANT SECRETARIES

|   |                |               |
|---|----------------|---------------|
| Dr M E McGraw and Dr E J Tizard:        | Talia Goddard  | 0117 342 8881 |
| Prof Moin Saleem and Dr Richard Coward: | Shelia Wood    | 0117 342 8880 |
| Dr Jan Dudley & Dr Carol Inward :       | Lisa Jefferies | 0117 342 8789 |
| Mr G Nicholls & Mr Woodward (Urology)   |                | 0117 342 8840 |

#### OTHER USEFUL NUMBERS

|                                     |                    |
|-------------------------------------|--------------------|
| Children's Renal Unit nurse station | 0117 342 8337/8624 |
| Community nurses                    | 0117 342 8548/9    |

\* We are grateful to the British Kidney Patient Association through which Dr Coward's post is part funded

## 4. ANALYSIS OF INPATIENT ADMISSIONS

### 4.1 BY DISTRICT OF RESIDENCE

Children are admitted from a wide geographical area. Close liaison with the local District Hospitals and the existence of outreach paediatric nephrology clinics does enable children to be returned to their own locality as soon as possible. In previous years data from the renal unit has been recorded according to admission by district health authority. From 2002-6 admissions were recorded according to Strategic Health Authorities, which were larger than previous DHAs so that a direct comparison could not be made. For 2002-2006 the data was presented for individual SHAs and in some cases local hospitals. From April 2006 the boundaries have changed yet again and figures are given for admissions and bed-days from PCTs.

Admissions are equivalent to patient spells ie the date of admission to discharge; this may include multiple consultant patient episodes. Although it appears that there has been a stabilization of admissions over the past few years the workload from the Southwest region has increased. Between 2006-2011 there has been a reduction in admissions from Wales but the increase in the SW admissions has resulted in no significant overall reduction in workload.

Fig. 4.1.1

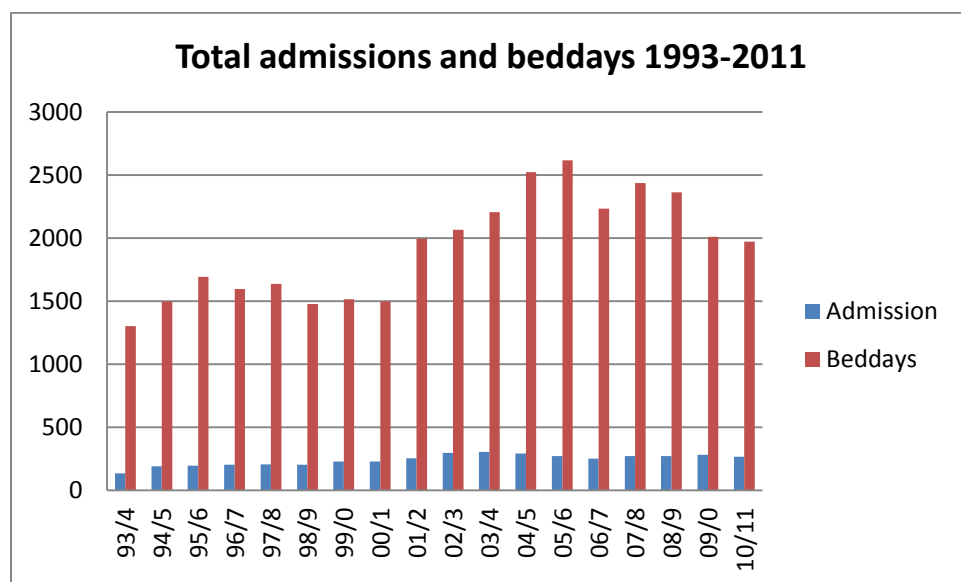


Fig 4.1.2 A: Admission by Strategic Health Authority residence: bed days 2002-06

| Strategic Health Authority        | 02/03       | 03/04       | 04/05       | 05/06       |
|-----------------------------------|-------------|-------------|-------------|-------------|
| Avon, Gloucestershire & Wiltshire | 922         | 933         | 987         | 1258        |
| Dorset and Somerset               | 238         | 318         | 304         | 337         |
| Hampshire and Isle of Wight       | 32          | 17          | 0           |             |
| South West Peninsula              | 376         | 363         | 394         | 240         |
| South and West Wales              | 484         | 556         | 836         | 770         |
| Other                             | 14          | 23          | 1           | 11          |
| <b>Total</b>                      | <b>2066</b> | <b>2205</b> | <b>2522</b> | <b>2616</b> |

Figure 4.1.2 B Admission by PCT : bed days 2006-2011

| New PCT                      | Code used in document | Population | Bed days 06/07 | Bed days 07/08 | Bed days 08/09 | Bed days 09/10 | Bed days 10/11 |
|------------------------------|-----------------------|------------|----------------|----------------|----------------|----------------|----------------|
| Gloucestershire              | A                     | 573,000    | 314            | 356            | 421            | 454            | 291            |
| South Gloucestershire        | B                     | 248,000    | 412            | 582            | 376            | 158            | 261            |
| Bristol Teaching             | C                     | 394,000    | 359            | 231            | 298            | 185            | 166            |
| North Somerset               | D                     | 193,000    | 98             | 16             | 29             | 61             | 106            |
| Bath & NE Somerset           | E                     | 172,000    | 85             | 15             | 11             | 32             | 0              |
| Swindon                      | F                     | 188,000    | 35             | 60             | 16             | 41             | 17             |
| Wiltshire                    | G                     | 445,000    | 28             | 23             | 116            | 87             | 83             |
| Somerset                     | H                     | 512,000    | 304            | 232            | 233            | 220            | 296            |
| Dorset                       | I                     | 400,000    |                | 2              | 0              | 75             | 7              |
| Bournemouth & Poole teaching | J                     | 301,000    |                | 0              | 0              | 0              | 0              |
| Cornwall Isles of Scilly     | K                     | 517,000    | 151            | 125            | 229            | 230            | 129            |
| Plymouth teaching            | L                     | 244,000    | 36             | 121            | 154            | 50             | 53             |
| Devon                        | M                     | 725,000    | 262            | 451            | 311            | 321            | 339            |
| Torbay Care Trust            | N                     | 133,000    | 3              | 2              | 6              | 28             | 17             |
| TOTAL S West                 |                       | 5,045,000  | 2087           | 2216           | 2200           | 2034           | 1765           |
| Other                        |                       |            | 0              | 13             | 2              | 32             | 23             |
| South and West Wales         |                       |            | 145            | 207            | 163            | 35             | 183            |
| Total                        |                       |            | 2232           | 2436           | 2363           | 2010           | 1971           |

Fig 4.1.3 A: Admission by SHA of residence: consultant patient episodes

| Strategic Health Authority       | 02/03      | 03/04      | 04/05      | 05/06      |
|----------------------------------|------------|------------|------------|------------|
| Avon Gloucestershire & Wiltshire | 148        | 139        | 140        | 146        |
| Dorset and Somerset              | 38         | 37         | 30         | 28         |
| Hampshire and Isle of Wight      | 3          | 2          | 0          | 0          |
| South West Peninsula             | 50         | 53         | 38         | 37         |
| South and West Wales             | 57         | 70         | 82         | 59         |
| Other                            | 1          | 2          | 1          | 1          |
| <b>Total</b>                     | <b>297</b> | <b>303</b> | <b>291</b> | <b>271</b> |

Fig 4.1.3B: Admission by PCT of residence: consultant patient episodes 2006-2011

| New PCT                   | Code used in document | Population | Admission 06/07 | Admission 07/08 | Admission 08/09 | Admission 09/10 | Admission 10/11 |
|---------------------------|-----------------------|------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Gloucester shire          | <b>A</b>              | 573,000    | 40              | 42              | 47              | 36              | 38              |
| South Gloucester shire    | <b>B</b>              | 248,000    | 40              | 60              | 39              | 26              | 27              |
| Bristol Teaching          | <b>C</b>              | 394,000    | 28              | 39              | 42              | 30              | 32              |
| North Somerset            | <b>D</b>              | 193,000    | 15              | 5               | 8               | 13              | 14              |
| Bath & NE Somerset        | <b>E</b>              | 172,000    | 10              | 2               | 4               | 5               | 0               |
| Swindon                   | <b>F</b>              | 188,000    | 4               | 5               | 1               | 7               | 2               |
| Wiltshire                 | <b>G</b>              | 445,000    | 8               | 7               | 13              | 16              | 17              |
| Somerset                  | <b>H</b>              | 512,000    | 37              | 32              | 35              | 40              | 43              |
| Dorset                    | <b>I</b>              | 400,000    |                 | 1               | 0               | 9               | 2               |
| Bournemouth & Poole teach | <b>J</b>              | 301,000    |                 | 0               | 0               | 0               | 0               |
| Cornwall Isles of Scilly  | <b>K</b>              | 517,000    | 19              | 11              | 14              | 20              | 21              |
| Plymouth teaching         | <b>L</b>              | 244,000    | 6               | 9               | 15              | 13              | 14              |
| Devon                     | <b>M</b>              | 725,000    | 17              | 34              | 34              | 46              | 38              |
| Torbay Care Trust         | <b>N</b>              | 133,000    | 2               | 1               | 1               | 3               | 5               |
| TOTAL SW                  |                       | 5,045,000  | 226             | 248             | 252             | 264             | 253             |
| Other                     |                       |            | 0               | 1               | 1               | 6               | 4               |
| South and West Wales      |                       |            | 26              | 22              | 17              | 10              | 8               |
| TOTAL                     |                       |            | 252             | 271             | 270             | 280             | 265             |

Fig 4.1.4 : Admission by referring hospital 2010-11

| Referring Hospital   | No of admissions | No of patients | Bed days    |
|----------------------|------------------|----------------|-------------|
| Barnstaple           | 15               | 4              | 185         |
| Bath                 | 15               | 5              | 78          |
| Bristol              | 73               | 28             | 533         |
| Cheltenham           | 4                | 4              | 22          |
| Exeter               | 8                | 6              | 60          |
| Gloucester           | 34               | 11             | 269         |
| Oxford               | 2                | 1              | 5           |
| Plymouth             | 27               | 10             | 136         |
| Swindon              | 4                | 4              | 22          |
| Taunton              | 36               | 11             | 241         |
| Torbay               | 7                | 4              | 28          |
| Truro                | 21               | 9              | 129         |
| Yeovil               | 9                | 5              | 62          |
| South and West Wales | 8                | 7              | 183         |
| Other                | 2                | 2              | 18          |
| <b>Total</b>         | <b>265</b>       | <b>111</b>     | <b>1971</b> |

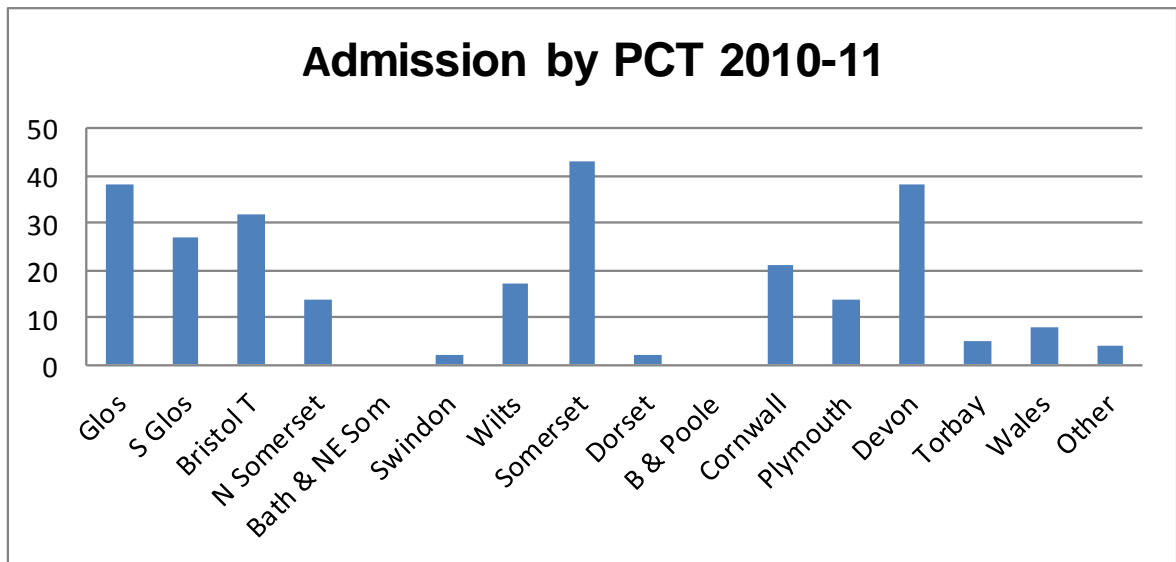
### South and West Wales

At the end of 2005 Cardiff reintroduced the inpatient service. Patients are admitted for renal transplantation and some access surgery but since 2006 other patients have been admitted to Cardiff. There remain a few patients who started their care in Bristol and chose to stay under the Bristol team rather than transfer back to Cardiff.

In 2010-11 there were 8 admissions in 7 patients. One patient was admitted with *acute kidney injury* (see p 11 for definition). She had a vasculitis for which she required plasma exchange which is not provided in South Wales. She occupied 12 (6.5%) bed days. The remaining 6 patients all had *chronic kidney disease* (see p 11 for definition) and occupied 171(93.5%) bed-days. Five patients underwent renal transplantation, 2 pre-emptive live donor and 3 deceased donor transplants. One newborn baby was admitted with chronic renal failure for which he required peritoneal dialysis. He was transferred back to wales on peritoneal dialysis but subsequently died. Of the chronic renal failure bed days, 159(92%) were related to the primary admission for the transplant; this included a prolonged admission in one child who had a complicated course with adenovirus and fungal infection.

In the Figures in this document numbers of admissions from district general hospitals from the Cardiff catchment area are amalgamated as originating from South and West Wales.

Fig 4.1.5 Admission by PCT



#### 4.2 BY AGE

Over the past year there has been a sustained increase in the admissions in the under six year olds this year accounting for 47.5% of the overall admissions. This year bed-days for the 0-6 year olds accounted for just over 51%

Fig 4.2.1: Percentage admissions by age

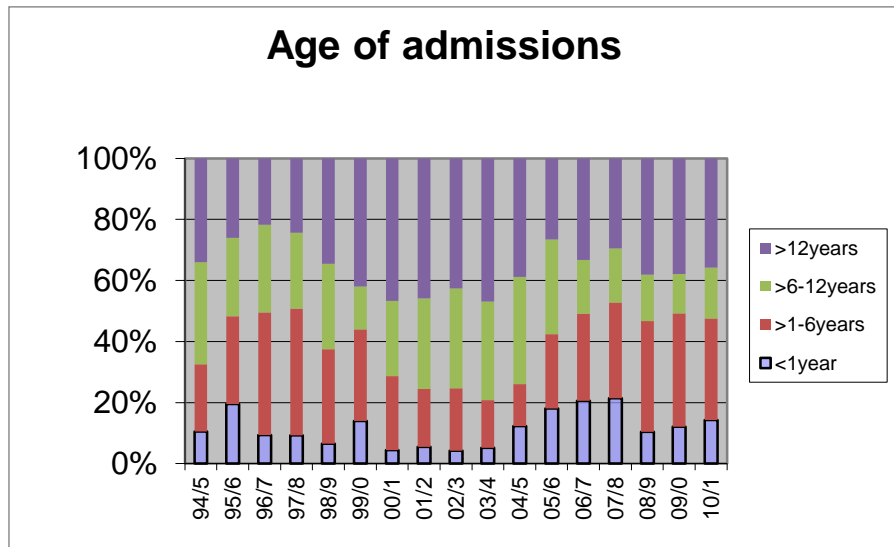
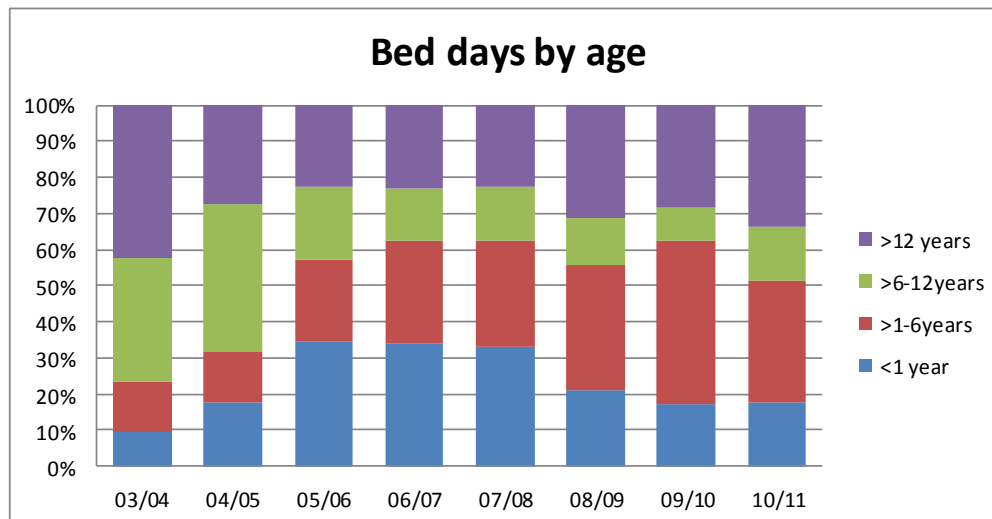


Fig 4.2.2 Bed days by age



#### 4.3. BY TYPE OF ADMISSION

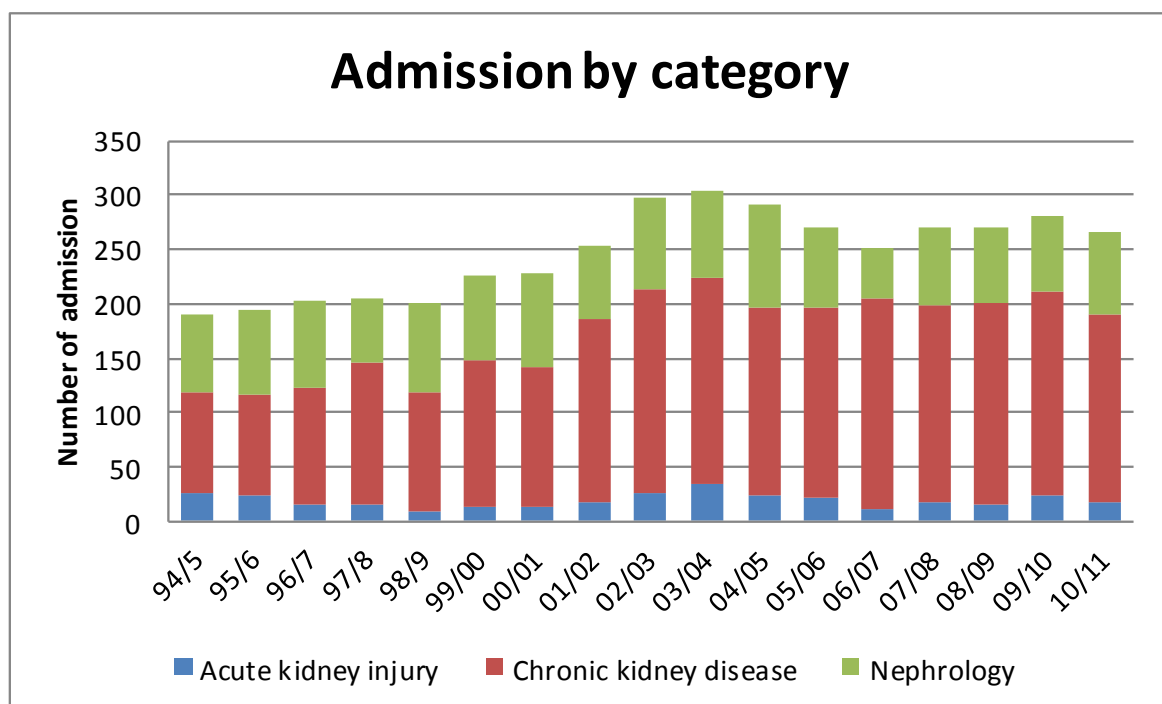
Overall there were 265 inpatient admissions occupying 1971 bed-days in 2010-11; this included PICU bed-days where the primary physician was renal. Three categories of patients are recognised:

- **Acute kidney injury (AKI):** those patients with a sudden onset of severe acute kidney failure who require careful medical management and often require dialysis;
- **Chronic kidney disease (CKD):** This includes both those children with severe renal failure who require dialysis or transplantation and those children with moderate kidney failure who may need dialysis and transplantation in the future;
- **Nephrology:** those children with a range of renal problems including glomerulonephritis, nephrotic syndrome, urological problems, urinary tract infection, hypertension and renal tubular disorders.

Fig 4.3.1: Numbers of admissions and bed-days occupied according to category. From 2005 this has included bed days in PICU when primary renal admission.

| Year    | Acute kidney Injury |                 | Chronic kidney disease |                 | Nephrology        |                 |
|---------|---------------------|-----------------|------------------------|-----------------|-------------------|-----------------|
|         | <i>Admissions</i>   | <i>Bed days</i> | <i>Admissions</i>      | <i>Bed days</i> | <i>Admissions</i> | <i>Bed days</i> |
| 1994/5  | 26                  | 334             | 92                     | 903             | 73                | 258             |
| 1995/6  | 23                  | 265             | 93                     | 1057            | 79                | 371             |
| 1996/7  | 15                  | 179             | 108                    | 1164            | 79                | 253             |
| 1997/8  | 15                  | 209             | 130                    | 1158            | 60                | 270             |
| 1998/9  | 8                   | 89              | 107                    | 921             | 87                | 466             |
| 1999/0  | 13                  | 153             | 136                    | 974             | 78                | 387             |
| 2000/1  | 13                  | 225             | 128                    | 822             | 87                | 449             |
| 2001/2  | 18                  | 167             | 169                    | 1312            | 66                | 516             |
| 2002/3  | 26                  | 280             | 187                    | 1442            | 84                | 344             |
| 2003/4  | 35                  | 488             | 188                    | 1389            | 80                | 328             |
| 2004/5  | 24                  | 369             | 173                    | 1512            | 94                | 641             |
| 2005/6  | 22                  | 445             | 175                    | 1919            | 74                | 252             |
| 2006/7  | 12                  | 194             | 192                    | 1822            | 48                | 216             |
| 2007/8  | 17                  | 343             | 181                    | 1505            | 73                | 588             |
| 2008/9  | 16                  | 218             | 185                    | 1709            | 69                | 436             |
| 2009/10 | 24                  | 357             | 188                    | 1317            | 68                | 336             |
| 2010/11 | 18                  | 222             | 172                    | 1290            | 75                | 459             |

Fig 4.3.2: Numbers of admissions according to category



## 5 ACUTE KIDNEY INJURY

### 5.1 DURATION OF ADMISSION

2010-11

There were 18 admissions in 18 patients occupying 222 bed-days. As would be expected all patients were admitted as emergencies. 11 patients required dialysis. All patients requiring dialysis were managed with haemodialysis. Five patients also started with a period of on intensive care. Two patients required plasma exchange. The average length of stay was 12.3 days with a range of 2-45days. There were 2 patients with prolonged admissions (20 days or more). One had developed AKI following an acute abdominal problem and he never recovered renal function and remains dialysis dependant. The other had an unusual cause of AKI due to rhabdomyolysis possibly secondary to EBV infection. He and the remaining 9 patients who had required dialysis recovered renal function.

### 5.2 AGES OF ADMISSION

| Age in years | 06/7 | 07/8 | 08/9 | 09/0 | 10/11 |
|--------------|------|------|------|------|-------|
| <1           | 2    | 2    | 1    | 2    | 0     |
| 1-6          | 8    | 5    | 3    | 13   | 9     |
| 6-12         | 0    | 6    | 9    | 7    | 7     |
| >12          | 2    | 2    | 3    | 2    | 2     |

### 5.3 SOURCE OF ADMISSION

Fig 5.3.1 A: Acute kidney injury according to PCT and Hospital (Fig 5.3.1B)

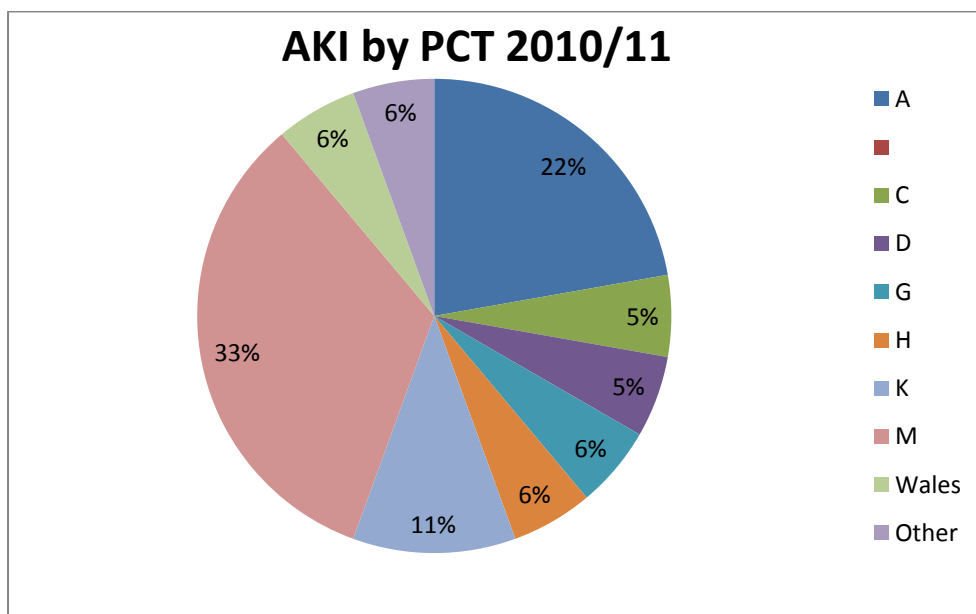
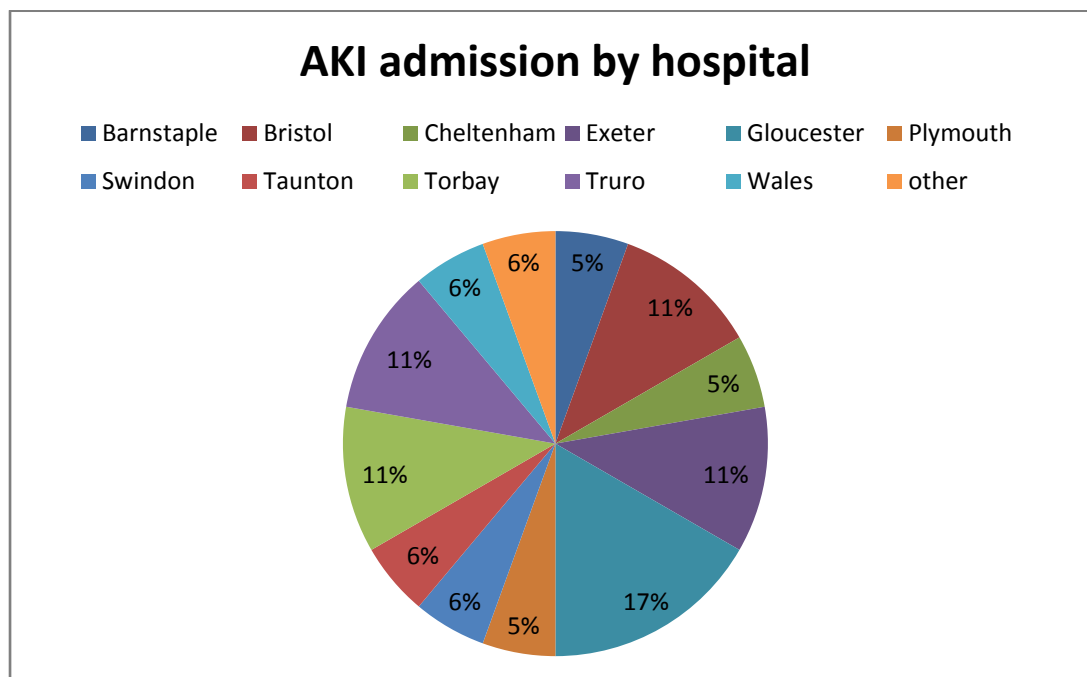


Fig 5.3.1B



#### 5.4 REASON FOR ADMISSION

| Diagnosis              | 2006-7 | 2007-8 | 2008-9 | 2009-10 | 2010-11 |
|------------------------|--------|--------|--------|---------|---------|
| HUS D+                 | 6 (5)  | 8(8)   | 12(11) | 14(14)  | 9(7)    |
| HUS D-                 | 1      | 1(1)   | 0      | 5(5)    | 2(0)    |
| ANCA pos<br>vasculitis |        | 3(3)   | 0      | 0       | 1(0)    |
| Sepsis/MOF             | 1(1)   |        | 1      | 2(1)    | 1(1)    |
| Obstruction            | 1      | 1      | 0      | 0       | 0       |
| Acute nephritis        |        | 4(1)   | 1      | 2       | 0       |
| Trauma                 |        |        | 1(1)   |         | 0       |
| ATN from D+V           |        |        |        |         | 2(0)    |
| Other                  | 3(1)   |        |        | 1       | 3(3)    |

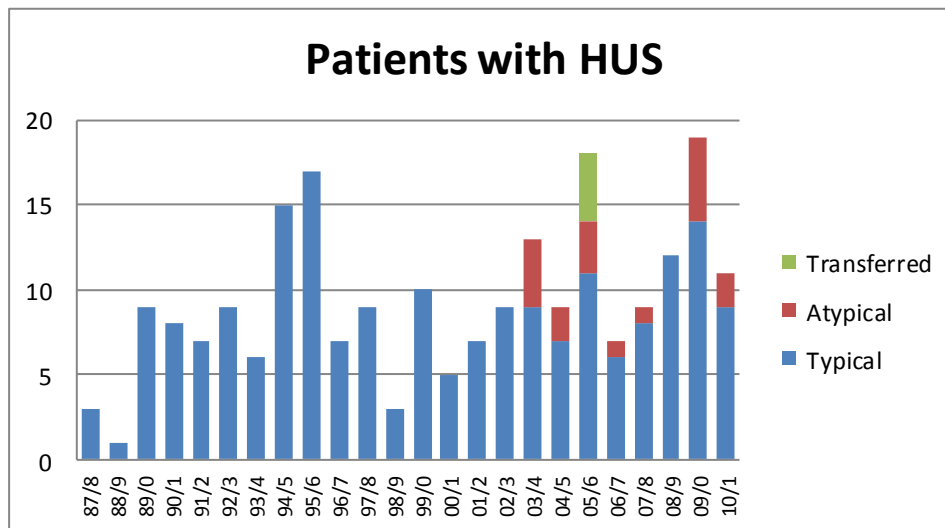
Number in brackets –number dialysed

Between 2010 and 2011 there were 11 admissions in 11 children with AKI due to Haemolytic Uraemic Syndrome (HUS). Nine had D+ (diarrhoea associated) HUS, one had pneumococcal HUS and one atypical HUS. This latter patient had plasma exchange (PE) as part of her treatment. Seven patients were managed with haemodialysis and four did not require dialysis. All made good recoveries and none remained on dialysis.

There is a continuing change in practice with all patients with AKI managed with haemodialysis this year.

HUS is the commonest cause of primary renal disease causing acute kidney injury in childhood. Between 1986 and 1989 an epidemiological survey in the United Kingdom found an incidence of nearly 2 cases per 100,000 children per annum. In a subsequent survey between February 1997 and January 2001 the incidence was 0.8 per 100,000 children under 15 years per annum. In the UK the predominant organism associated with HUS is E Coli 0157:H7. Whilst the diagnosis of enterohaemorrhagic E. coli (EHEC) has increased the incidence of HUS has overall remained stable over the past 20 years but local epidemics cause the fluctuations in incidence year on year. A further survey of HUS is about to commence via the BPSU.

Fig 5.4.1: Numbers of admissions of children with Haemolytic Uraemic Syndrome (HUS) . (Divided into D+ typical and D- Atypical since 2003/4)



## 5.5 PLASMA EXCHANGE

Plasma exchange is a well recognised therapy for a number of nephrological conditions. Plasma exchange is generally performed by the apheresis team from North Bristol Trust. The workload of plasma exchange has been sustained as we accrue a number of chronic patients who respond to PE. However this may change with the introduction of eculizumab for the management of atypical HUS. In 2010-11 eight patients underwent PE. The 2 patients with post transplant FSGS were the same patients who continue to be managed with PE over the previous 2 years but as their disease has become more stable they have required less plasma exchange. The marked increase in procedures has been due to 3 children with atypical HUS who accounted for 200 procedures in 2009-10 and 2 further patients presenting in 2010-11. One of these only had one episode of HUS and so far has not relapsed and has normal renal function. However the second requires chronic PE to maintain remission. One child has now developed established renal failure requiring peritoneal dialysis whilst the others all have normal renal function.

We are extremely grateful to the plasma exchange team who have again provided the renal unit with an excellent service over this period.

Fig 5.5.1 Number of Plasma exchanges

| Condition                              | No Pts | No. PEs | No Pts | No PEs | No Pts | No PEs | No Pts | No PEs | No Pts | No PEs |
|--|--------|---------|--------|--------|--------|--------|--------|--------|--------|--------|
|  | 06/7   | 06/7    | 07/8   | 07/8   | 08/9   | 08/9   | 09/0   | 09/0   | 10/1   | 10/1   |
| Haemolytic Uraemic syndrome (atypical) | 1      | 8       |        |        | 1      | 44     | 3      | 200    | 5      | 248    |
| HUS(D+)                                | 1      | 7       | 2      | 14     | 3      | 15     |        | 5      |        |        |
| RPGN(unknown aetiology)                |        |         |        |        |        |        |        |        |        |        |
| pANCA vasculitis                       |        |         | 2      | 14     |        |        |        |        | 1      | 8      |
| Wegener's granulomatosis               |        |         | 1      | 7      |        |        |        |        |        |        |
| Primary FSGS                           |        |         |        |        | 1      | 19     |        |        |        |        |
| Post Transplant relapse of FSGS        | 1      | 46      | 1      | 46     | 2      | 88     | 2      | 168    | 2      | 89     |
| Post Tx relapse of MCGN                |        |         | 1      | 42     |        |        |        |        |        |        |
| Total                                  | 3      | 61      | 7      | 123    | 7      | 166    | 5      | 373    | 8      | 345    |

## 5.6 ACUTE KIDNEY INJURY SUPPORT PICU

Between 2010-11 the workload of managing acute kidney injury on the Paediatric Intensive Care Unit (PICU) has remained stable with meningococemia remaining a low cause of acute kidney injury since the introduction of meningococcal vaccine

Fig 5.6.1 : Acute kidney injury in Paediatric Intensive Care: modes of treatment

| Year                | 96/7 | 97/8 | 98/9 | 99/0 | 00/1 | 01/2 | 02/3 | 03/4 | 04/5 | 05/6 | 06/7 | 07/8 |
|---------------------|------|------|------|------|------|------|------|------|------|------|------|------|
| No admissions       | 35   | 41   | 36   | 55   | 67   | 43   | 43   | 57   | 39   | 60   | 42   | 49   |
| Peritoneal dialysis | 31   | 28   | 31   | 48   | 60   | 34   | 37   | 42   | 27   | 43   | 31   | 38   |
| Haemofiltration     | 6    | 14   | 5    | 11   | 14   | 8    | 11   | 19   | 11   | 15   | 11   | 12   |
| Haemodialysis       |      |      |      |      |      | 4    | 1    | 8    | 1    | 11   | 4    | 4    |
| Days of RRT         | 214  | 264  | 142  | 246  | 276  | 164  | 216  | 332  | 164  | 290  | 191  | 225  |
| Mortality %         | 22   | 17   | 22   | 20   | 18   | 14   | 26   | 30   | 18   | 15   | 33   | 20   |

| Year                | 08/9 | 09/10 | 10/11 |
|---------------------|------|-------|-------|
| No admissions       | 46   | 39    | 48    |
| Peritoneal dialysis | 34   | 27    | 31    |
| Haemofiltration     | 17   | 12    | 16    |
| Haemodialysis       |      |       | 5     |
| Days of RRT         | 216  | 207   | 249   |
| Mortality %         | 9    | 22    | 21    |

Fig 5.6.2: Acute kidney injury in Paediatric Intensive Care: underlying diagnosis  
(Full year's data for 2010-11 not available at present)

| Aetiology     | 96/<br>7 | 97/<br>8 | 98/<br>9 | 99/<br>0 | 00/<br>1 | 01/<br>2 | 02/<br>3 | 03/<br>4 | 04/<br>5 | 05/<br>6 | 06/<br>7 | 07/<br>8 |
|---------------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|
| Cardiac       | 29       | 21       | 19       | 30       | 43       | 22       | 22       | 31       | 26       | 28       | 24       | 30       |
| Meningococcal | 3        | 10       | 6        | 12       | 7        | 7        | 2        | 9        | 2        | 3        | 0        | 2        |
| Other sepsis  |          |          | 8        | 5        | 10       | 0        | 1        | 6        | 3        | 6        | 2        | 1        |
| Renal         | 2        | 3        | 2        | 2        | 1        | 5        | 6        | 4        | 3        | 13       | 8        | 9        |
| Oncological   |          | 2        |          | 3        |          | 3        | 1        | 1        | 2        | 0        | 3        | 4        |
| Other         | 1        | 6        | 1        | 3        | 6        | 6        | 11       | 6        | 3        | 10       | 5        | 3        |

| Aetiology     | 08/9 | 09/10 |
|---------------|------|-------|
| Cardiac       | 23   | 27    |
| Meningococcal | 3    | 0     |
| Other sepsis  | 9    | 1     |
| Renal         | 5    | 6     |
| Oncological   | 0    | 1     |
| Other         | 6    | 4     |

## 6 CHRONIC KIDNEY DISEASE

Established renal failure (ERF) in children is rare with an incidence of around 2 per million total population per annum. The renal replacement programme in Bristol began in 1976 and the number of children on the programme accumulated steeply over the early years. Although there has been relative stability in numbers over the past 2 year the increase in younger patients-especially the infants results in a steady increase in the end-stage renal failure workload.

When the programme first started 57% of children with end stage renal failure were on dialysis. This fell over subsequent years to 12% of children on the programme being on dialysis in 1996 but had risen again to 35.8% at the end of 2005 and fluctuated since being 23.7% at the end of 2010.

The most recent national data from 2009 showed 24% on dialysis , 67% with a functioning transplant and 9% unknown. (From UK Renal Registry 13<sup>th</sup> Annual report 2010). Therefore our cohort are similar to the national cohort.

Nationally 60% of those on dialysis are on peritoneal dialysis. As of December 2010, 42% of our population were on peritoneal dialysis. This is a continuing decline in our PD population and increase in the HD population. This does fluctuate year on year but this there was an increase use of HD in children with complex conditions which preclude PD

The dialysis data and transplants under follow up(Fig 11) does not include the entire cohort of patients from South and West Wales as some of these patients may not have been seen at the Bristol Unit. However it does include patients from Wales who are entirely managed by Bristol. The number of grafts performed includes the patients from South and West Wales.

Fig 6.0 A: Renal replacement therapy.

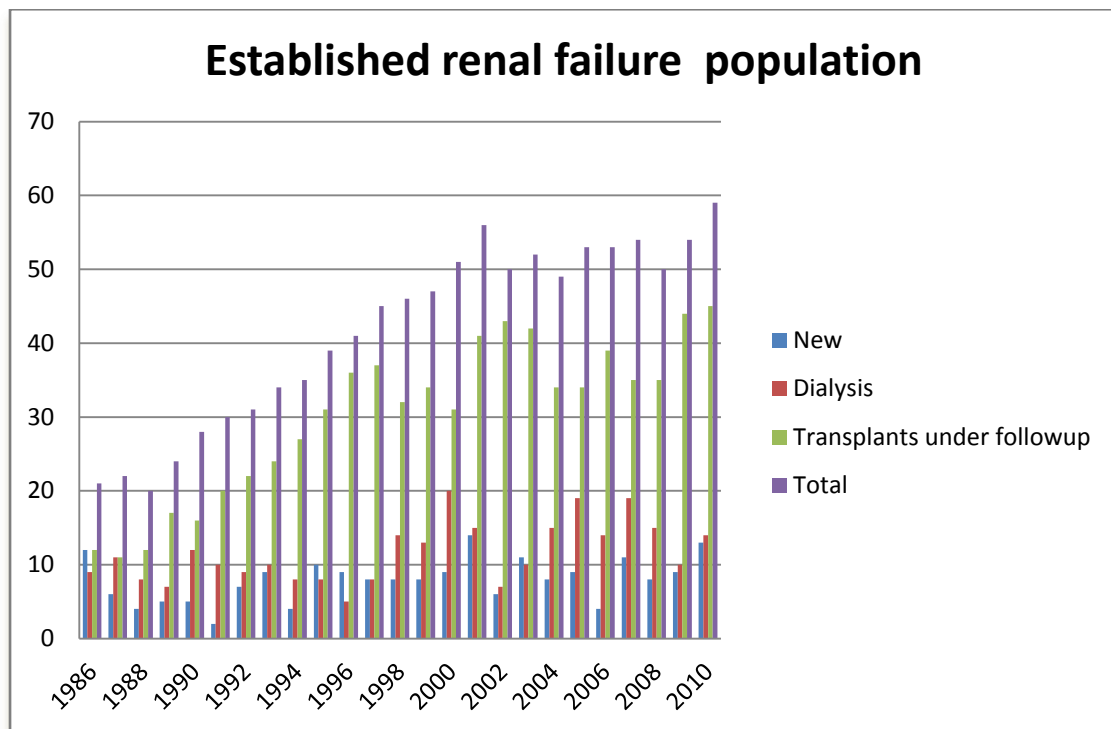
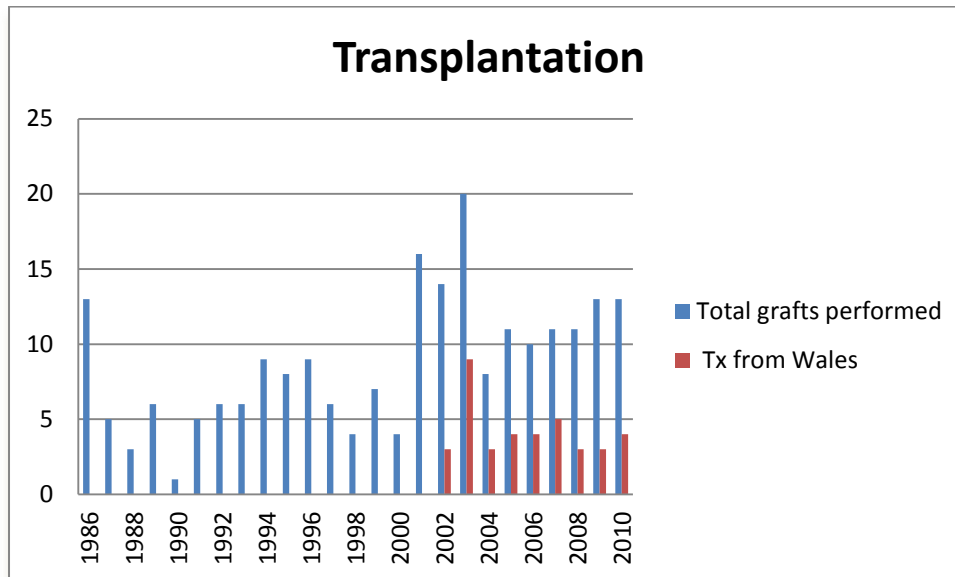


Fig 6.0B



### 6.1 DURATION OF ADMISSION

The number of admissions over the past few years has been stable however it represents a sustained increase in SW activity as since 2006 Cardiff has reopened the inpatient Unit such that admissions from South and West Wales are significantly reduced. The mean length of stay has remained low in 2010-11. We continue to strive to reduce length of stay and with support from the community team this has proved successful. Nearly 75% of these patients were admitted as emergencies and these accounted for 1022(79.2%) of beddays. Of the 257 planned beddays 113(43.9%) were for 7 live related donor transplants with a mean admission of 16.1 bed-days.

Fig 6.1.1

|                         |                |                |                |                |                       |
|-------------------------|----------------|----------------|----------------|----------------|-----------------------|
|                         | 2006-7         | 2007-8         | 2008-9         | 2009-10        | 2010-11               |
| Number of admissions    | 192            | 181            | 185            | 188            | 172                   |
| % total admissions      | 76.1           | 66.7           | 68.5           | 67.1           | 64.9                  |
| Number of bed-days      | 1822           | 1505           | 1709           | 1317           | 1290                  |
| % total bed-days        | 81.6           | 63.6           | 72.3           | 65.5           | 65.4                  |
| Length of stay :mean    | 9.5            | 8.3            | 9.2            | 7.0            | 7.5                   |
| median                  | 4              | 5              | 4              | 3              | 4                     |
| Single admission (%)    | 21(10.9)       | 16(8.8)        | 20(10.8)       | 14(7.4)        | 14(8.1)               |
| Short stay<3 days (%)   | 66(34.4)       | 56(30.9)       | 58(31.1)       | 66(35.1)       | 61(35.5)              |
| Admission <10days(%)    | 129(67.2)      | 128(70.7)      | 129(69.7)      | 150(79.8)      | 129(75.0)             |
| Admission 10-28 days(%) | 53(27.6)       | 38(21.0)       | 48(25.9)       | 31(16.4)       | 38(22.0)              |
| Admission > 28 days(%)  | 10(5.2)        | 5(2.7)         | 8(4.3)         | 7(3.7)         | 5(2.9)                |
| Total admission days    | No of patients | No of patients | No of patients | No of patients | No of patients        |
| <20                     | 30             | 28             | 28             | 25             | 32                    |
| 20-40                   | 12             | 10             | 18             | 10             | 8                     |
| >40-70                  | 5              | 8              | 7              | 8              | 8                     |
| >70-90                  | 0              | 1              | 1              | 2              | 2                     |
| >90                     | 7              | 3              | 4              | 2              | 1                     |
| Emergency admission (%) |                |                |                |                | 125(72.6)             |
| Bed days                |                |                |                |                | 1022(79.2)            |
| Semi-planned beddays    |                |                |                |                | 2(1.1)<br>11(0.8)     |
| Planned beddays         |                |                |                |                | 45(26.1)<br>257(19.9) |

Fig 6.1.2: Duration of admission for children with chronic renal failure (by percentage) 1996-2006.

|            | 96/97     | 97/98     | 98/9      | 99/00       | 00/01       | 01/02       | 02/03       | 03/04       | 04/05       | 05/06       |
|------------|-----------|-----------|-----------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|
| <10 days   | <b>66</b> | <b>77</b> | <b>79</b> | <b>78.6</b> | <b>72.5</b> | <b>75.2</b> | <b>73.2</b> | <b>79.2</b> | <b>76.3</b> | <b>69.7</b> |
| 10-28 days | <b>23</b> | <b>16</b> | <b>15</b> | <b>17</b>   | <b>20</b>   | <b>19.5</b> | <b>22.5</b> | <b>17.0</b> | <b>17.9</b> | <b>21.7</b> |
| >28 days   | <b>11</b> | <b>7</b>  | <b>6</b>  | <b>4.4</b>  | <b>6.9</b>  | <b>5.3</b>  | <b>4.2</b>  | <b>3.7</b>  | <b>6.3</b>  | <b>8.5</b>  |

In 2010-11 three patients had three single admissions of over 60 days. One was a child who underwent deceased donor transplant and had severe infectious complications with adenovirus and candida peritonitis. She made an excellent recovery. The second, a child, also post-transplant developed a lymphocele and another complicated course. The third child with atypical HUS had severe peritonitis for which he required removal of his PD catheter and transfer to haemodialysis, but had prolonged sepsis which was difficult to eradicate. . These long admissions highlight the intensive nature of managing children with severe chronic renal failure.

For those who have recurrent admissions it is the total time in hospital that is important. In 2010-11 there was 1 patient with greater than 90 days as an inpatient; He had a deceased donor transplant and multiple complication including the lymphocele (mentioned above), rejection and renal artery stenosis.

Fig 6.1.3: Duration of admission of those with multiple admissions with chronic renal failure (number of patients)(1996-2006)

| Total days in hospital | 96/7 | 97/8 | 98/9 | 99/0 | 00/1 | 01/2 | 02/3 | 03/4 | 04/5 | 05/6 |
|------------------------|------|------|------|------|------|------|------|------|------|------|
| <20                    | 4    | 9    | 6    | 7    | 8    | 13   | 14   | 20   | 34   | 28   |
| 20 - 40                | 5    | 6    | 6    | 6    | 6    | 16   | 11   | 13   | 6    | 10   |
| >40 - 70               | 8    | 3    | 4    | 4    | 6    | 6    | 6    | 5    | 6    | 6    |
| >70 - 90               | 1    | 1    | 0    | 2    | 2    | 3    | 4    | 3    | 3    | 3    |
| >90                    | 3    | 4    | 2    | 2    | 0    | 0    | 1    | 2    | 3    | 6    |

## 6.2 AGES OF ADMISSION

The ages of admission are summarised in Figure 14. The numbers of infants starting dialysis each year fluctuates. In the last year there have been no new infants requiring dialysis and therefore this group is underrepresented compared with recent years.

Fig 6.2.1 A: Ages of admission of children with chronic failure

Number of admissions (% of total bed-days) in each age group

| Age yrs | 96/97 No(%) | 97/8 No(%) | 98/9 No(%) | 99/00 No(%) | 00/01 No(%) | 01/02 No(%) | 02/03 No(%) | 03/4 No(%) | 04/5 No(%) | 05/6 No(%) |
|---------|-------------|------------|------------|-------------|-------------|-------------|-------------|------------|------------|------------|
| < 1     | 13(12)      | 12(18)     | 6(9)       | 4(20)       | 4(3)        | 11(7)       | 5(1)        | 8(11)      | 23(21)     | 38(41)     |
| >1-6    | 39(61)      | 61(42)     | 47(41)     | 38(32)      | 27(21)      | 23(11)      | 33(10)      | 16(7)      | 16(10)     | 37(20)     |
| >6-12   | 29(23)      | 23(18)     | 17(22)     | 18(16)      | 26(20)      | 42(25)      | 59(34)      | 69(37)     | 62(43)     | 52(21)     |
| >12     | 27(34)      | 34(22)     | 37(28)     | 41(31)      | 71(55)      | 92(57)      | 90(55)      | 95(45)     | 72(26)     | 48(18)     |

Fig 6.2.1 B: Numbers of admission by age 2006-11

| Age   | 2006-7 | 2007-8 | 2008-9 | 2009-10 | 2010-11 |
|-------|--------|--------|--------|---------|---------|
| <1    | 46     | 26     | 21     | 18      | 7       |
| 1-6   | 53     | 63     | 77     | 71      | 65      |
| >6-12 | 24     | 25     | 13     | 48      | 25      |
| >12   | 69     | 67     | 74     | 88      | 75      |
| Total | 192    | 181    | 185    | 188     | 172     |

Fig 6.2.2: Bed days by age 2006-11 (no. (%))

| Age   | 2006-7    | 2007-8    | 2008-9    | 2009-10   | 2010-11   |
|-------|-----------|-----------|-----------|-----------|-----------|
| <1    | 713(39.1) | 400(26.6) | 419(24.5) | 185(14.0) | 56(4.3)   |
| 1-6   | 472(25.9) | 523(34.7) | 595(34.7) | 604(45.9) | 495(38.3) |
| >6-12 | 235(12.8) | 118(7.8)  | 93(5.4)   | 48(3.6)   | 171(13.2) |
| >12   | 402(22.0) | 464(30.7) | 603(35.2) | 480(36.4) | 568(44.0) |
| Total | 1822      | 1505      | 1709      | 1317      | 1290      |

## 6.3 SOURCE OF ADMISSION

The incidence of end stage renal failure in children is only 2 per million total population per annum and we would therefore expect 8 new patients per year to the programme in the southwest. For 2006-11 the new patients to the programme are shown below

Fig 6.3.1

|            | 2006-7 | 2007-8 | 2008-9 | 2009-10 | 2010-11 |
|------------|--------|--------|--------|---------|---------|
| PD         | 2      | 4      | 2      | 1       | 6**     |
| HD         | 2      | 4      | 2      | 7       | 3       |
| Transplant |        | 3*     | 3      | 1       | 4       |
| Total      | 4      | 11     | 7      | 9       | 13      |

\* one Transplant transferred in

\*\* one transferred in on CCPD

Renal failure in childhood is a life limiting disease but mortality is low in childhood. In between January 2010-January 11 there was 1 death. This was a boy with ERF associated with posterior urethral valves who required dialysis from birth. He was established on PD and was transferred back to Wales to continue this but unfortunately did not survive due to other complications. A second boy with dysplastic kidneys who had required dialysis since birth died during the year April 2010-April 2011. In addition to his renal failure he had developed a hepatoblastoma and following surgery and chemotherapy developed a fungal peritonitis. He had major problems with dialysis access and subsequently died.

The prevalence of chronic renal failure is less well defined but is at least 50 per million children per annum. In common with other low volume high cost specialities the addition of one new patient can have a significant impact of the services purchased by one Health District. Direct comparison with earlier years is difficult because of the change in purchasing authority boundaries. Figures 15A, B and C illustrate the marked variation between years in a single district. This variation, both within and between districts makes predictions for contracting guidance extremely difficult. For 2006-11 Admissions by PCT have been included.

Fig 6.3.2 A: Districts of admission of children with chronic renal failure 1996-2002

| DISTRICT                             | No of admissions<br>1996/7 | No of admissions<br>1997/8 | No of admissions<br>1998/9 | No of admissions<br>1999/00 | No of admissions<br>2000/01 | No of admissions<br>2001/02 |
|--------------------------------------|----------------------------|----------------------------|----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Avon<br>(excludes Bath until 96/97)  | 46                         | 68                         | 43                         | 50                          | 59                          | 60                          |
| Bath & Wilts (incl Bath until 96/97) | 19                         | 29                         | 18                         | 23                          | 10                          | 13                          |
| Cornwall                             | 3                          | 1                          | 0                          | 1                           | 7                           | 21                          |
| Gloucester                           | 8                          | 9                          | 6                          | 28                          | 19                          | 29                          |
| North & East Devon                   | 15                         | 5                          | 10                         | 13                          | 8                           | 12                          |
| S&W Devon                            | 8                          | 4                          | 10                         | 1                           | 4                           | 10                          |
| Somerset                             | 4                          | 10                         | 18                         | 18                          | 14                          | 15                          |
| South and West Wales                 |                            |                            |                            |                             |                             | 6                           |
| Others                               | 5                          | 3                          | 2                          | 2                           | 7                           | 3                           |
| TOTAL                                | 108                        | 130                        | 107                        | 136                         | 128                         | 169                         |

Fig 6.3.2 B: Admission of children with chronic renal failure by Strategic Health Authority 2002-6

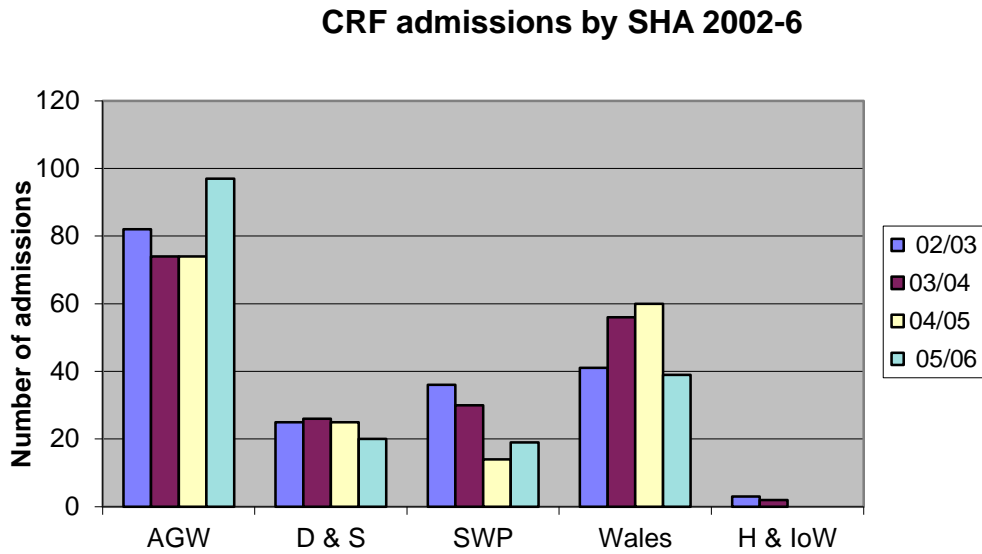


Fig 6.3.2 C: Admission of children with chronic renal failure by PCT 2006-11

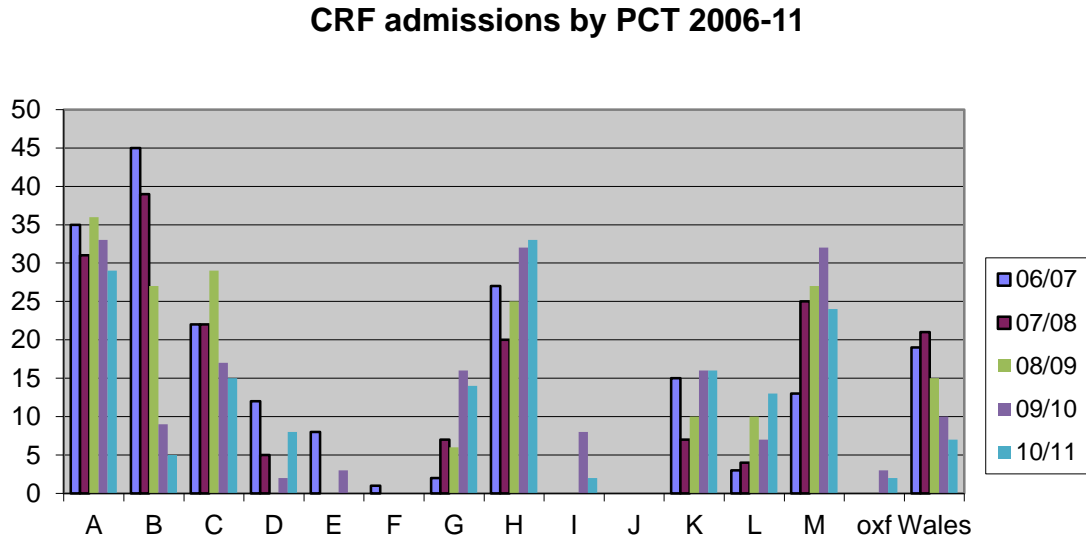


Fig 6.3.3 A: Admission of children with chronic renal failure by District General Hospital 2002-10

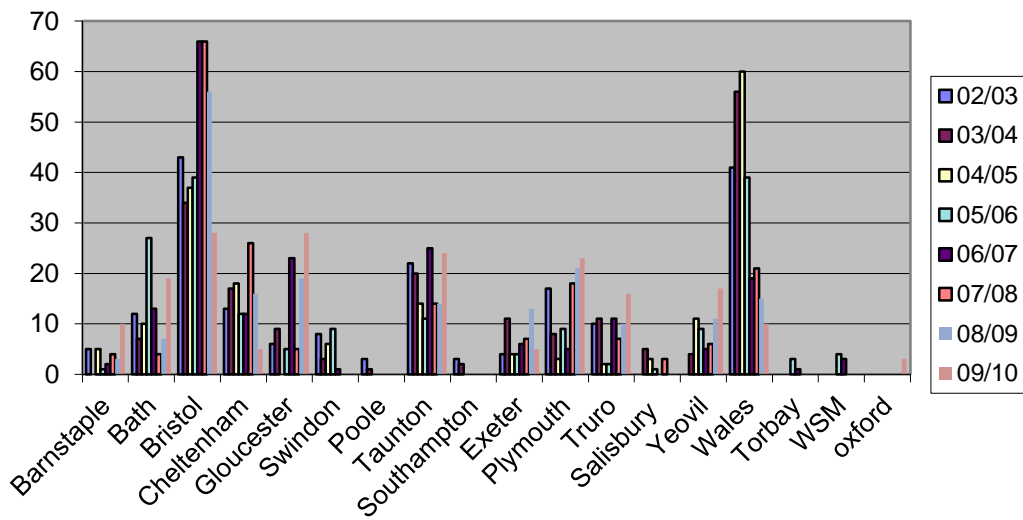
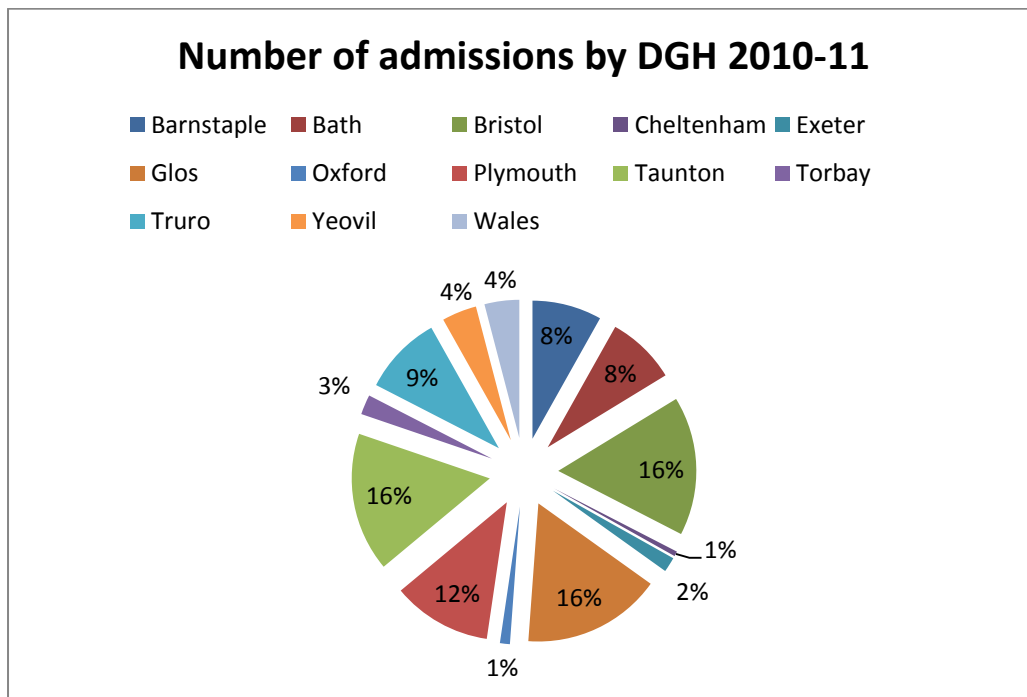


Fig 6.3.3 B Admission of children with chronic renal failure by District General Hospital 2010-11



## 6.4 REASON FOR ADMISSION

### a) Peritoneal dialysis (PD)

In 2010-11 there were 3 admissions in 3 children who were commenced on PD.

At the end of Dec 2010 there were 6 children on peritoneal dialysis from the SW region, all on Continuous Cycling Peritoneal Dialysis (CCPD).

### b) Peritonitis and other peritoneal dialysis related complications

The annual review of end stage renal failure patients identified 8 episodes of peritonitis in 3 patients 2010-11. Five of these episodes were in one patient and 2 of these episodes were culture negative. The peritonitis rate over 3 years was at 1 in 12 patient months is just on the BAPN Standard which is a peritonitis rate of <1/12 patient months averaged over 3 years. The 3 year data has improved from last year when it was 1 in 9 patient months reflecting the marked improvement since 2007/8. We will continue to strive to improve on the current rates.

The table below shows data for the SW region and included South and West Wales for both 2002/3 and 2003/4.

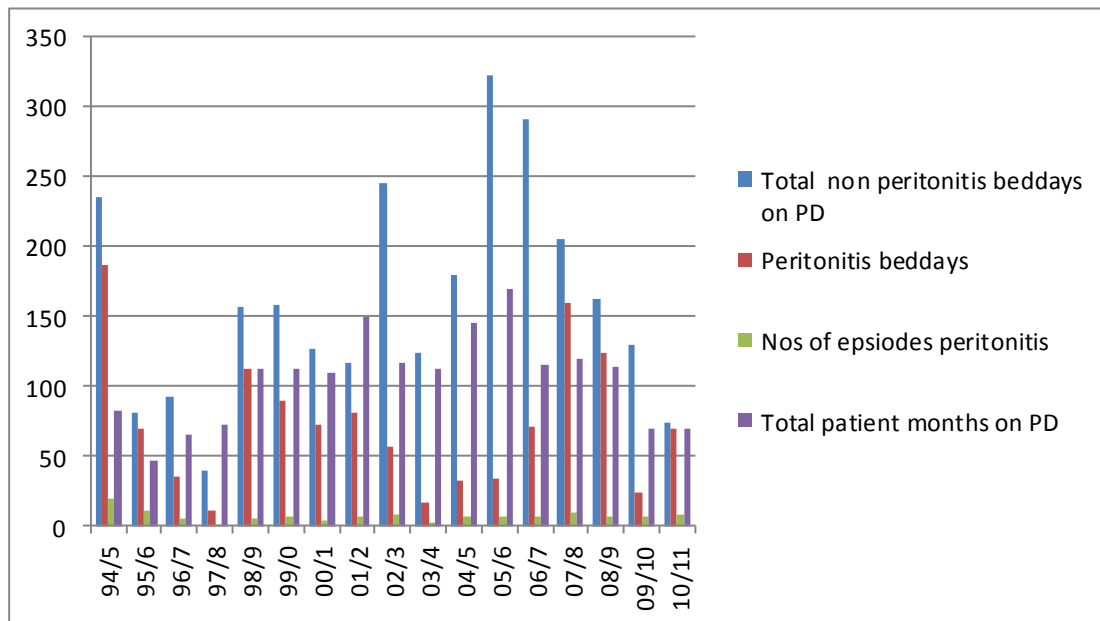
Fig 6.4.1 Peritonitis rates 2000-2011

|                         | 0/01   | 1/02   | 2/03                         | 3/04                         | 4/05  | 5/06 | 6/07   | 7/08   |
|-------------------------|--------|--------|------------------------------|------------------------------|-------|------|--------|--------|
| PD months               | 109    | 150    | 116 (inc South & West Wales) | 113 (inc South & West Wales) | 125   | 140  | 115    | 119    |
| Episodes of peritonitis | 8      | 12     | 11                           | 8                            | 19    | 6    | 20     | 20     |
| Episodes per PD months  | 1:13.6 | 1:12.5 | 1:10.5                       | 1:14.1                       | 1:6.6 | 1:23 | 1:5.75 | 1:5.95 |

|                         | 08/09 | 09/10 | 10/11  |
|-------------------------|-------|-------|--------|
| PD Months               | 114   | 70    | 69     |
| Episodes of peritonitis | 7     | 7     | 8      |
| Episodes per PD months  | 1:16  | 1:10  | 1: 8.6 |

In 2010-11 there were eight admissions in 3 patients for a primary diagnosis of peritonitis occupying 70 bed days. One patient was admitted 6 times for recurrent peritonitis. Some of these episodes were culture negative and this coincided with a problem with Extraneal PD fluid which resulted in sterile peritonitis and some of these episodes were attributed to this. One patient had very severe peritonitis and had to be converted to HD. Another was admitted for different compliant but developed fungal peritonitis from which he died. There were a further 14 admissions in 7 patients who were on peritoneal dialysis for other complications of chronic renal failure/dialysis occupying 74 bed days.

Fig 6.4.2: Peritoneal Dialysis Admissions (includes data for South and West Wales 2002-2006)

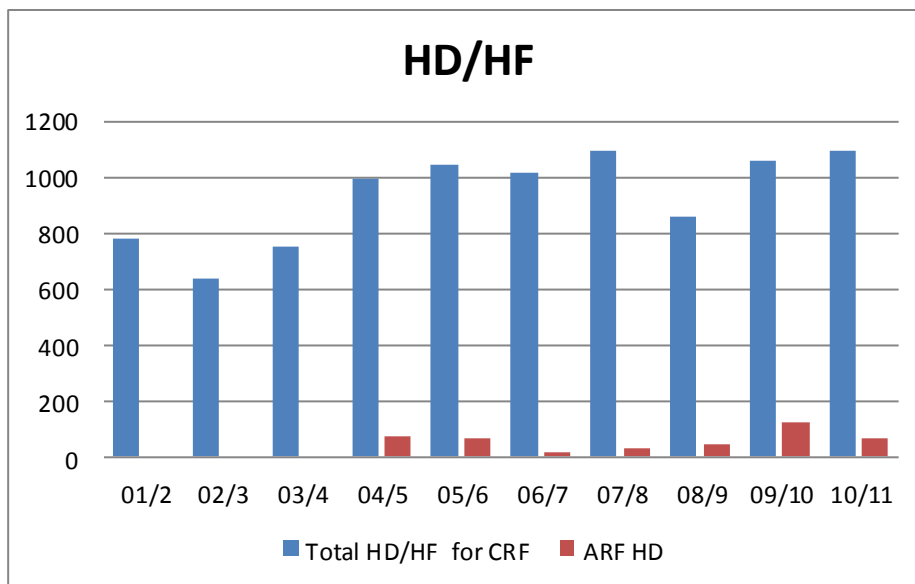


c) Haemodialysis and haemodialysis related problems

In 2010-11 there were 43 admissions in 10 patients occupying 186 bed-days in patients established on HD. In addition there was a further admission in one patient who was commenced on HD after his transplant failed after nearly 15 years accounting for 8 bed days. One patient had been admitted with AKI and started on HD following a period of haemofiltration. His primary admission is included in the AKI days. Therefore 194 is a more accurate total of HD bed days. As is common, individual complex patients account for many admissions and one teenager with problems with hypertension accounted for 8 admissions and 64(33%) of bed days. Another child with problems with compliance accounted for 11 admissions and 30 (15%) bed days.

During the year April 2010-11, 11 patients required haemodialysis for chronic renal failure and 1096 dialyses were performed. At the start of 2010 there were 5 patients on HD from the Southwest Region. At the end of 2010 there were 8 patients from the Southwest region on HD.

Fig 6.4.3 Numbers of procedures



d) Transplantation

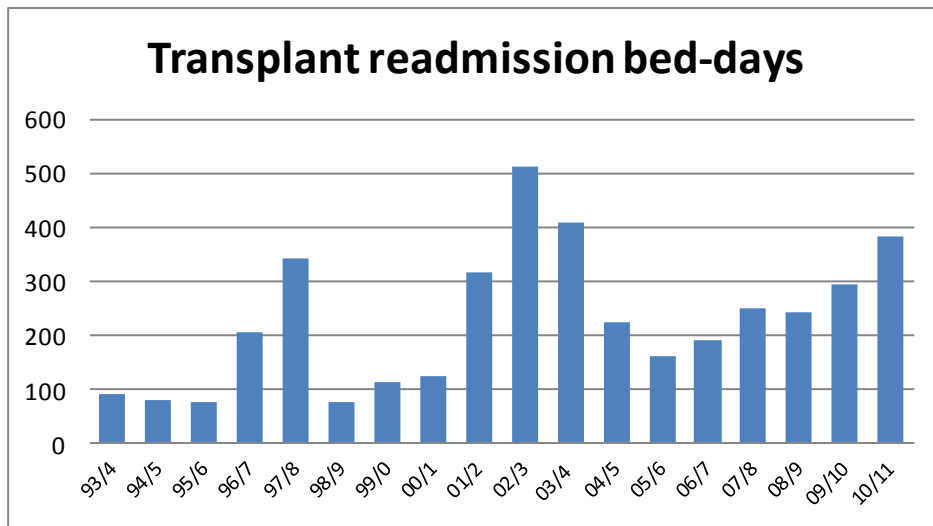
Transplant and dialysis statistics are generally reported at end of calendar year. During 2010 there were 13 transplants. Recently the numbers of transplants have been stable but the fall since the early part of the decade may relate to the new kidney allocation scheme which was introduced in 2006. This aims to improve the matching but may result in a longer wait for transplant. However the equity of access to transplants for children is continually being monitored and adjustments to the matching scheme are being made.

2010-11

To compare data with the other admissions, data for transplants is also calculated according to the financial year. There were 15 transplants performed between April 2010-April 2011 including 5 in patients from South and West Wales. These fifteen included 7 live donor transplants, and 8 deceased donor transplants. Twelve were first transplants and eight pre-emptive. One had a kidney from a donor after cardiac death(DCD).These 15 children receiving transplants between April 2010-April 2011 spent a total of 329 days in hospital for their primary admission giving an average length of stay of 21.9 days with a range of 14-87 days. This included one child with major infectious complications of adenovirus and Candida peritonitis. She had a prolong admission and excluding her the average length of stay for the remaining 14 patients was 17.2 days. There were two patients who had a renal biopsy during their first admission, one showed an interstitial nephritis and the second recovering acute tubular necrosis.

There were 52 further admissions in 22 children with transplants occupying a total 382 bed-days (1-58 days). Nine of these children had had transplants during the year. Eight admissions and 132 bed-days were in one boy who had multiple problems post-transplant . By the end of March 2011 all 15 patients transplanted during the previous year April 10-April 11 had successfully functioning transplants although 2 had continuing problems with renal dysfunction

Fig 6.4.4 Transplantation readmission: Bed-days



**Fig 6.4.5 ESRF population at end December (patients followed up in Southwest only)**

|                   | < 2 yrs | 2-5yrs | 5-10yrs | 10-15yrs | >15 yrs | Total |
|-------------------|---------|--------|---------|----------|---------|-------|
| <b>HD</b>         |         |        |         |          |         |       |
| 2003              | 1       | 0      | 1       | 1        | 0       | 3     |
| 2004              | 2       | 0      | 2       | 1        | 1       | 6     |
| 2005              | 1       | 0      | 2       | 2        | 2       | 7     |
| 2006              | 1       | 0      | 0       | 1        | 3       | 5     |
| 2007              | 3       | 1      | 0       | 1        | 2       | 7     |
| 2008              | 1       | 2      | 0       | 1        | 3       | 7     |
| 2009              | 2       | 0      | 0       | 1        | 2       | 5     |
| 2010              | 0       | 2      | 1       | 2        | 3       | 8     |
|                   |         |        |         |          |         |       |
| <b>CCPD</b>       |         |        |         |          |         |       |
| 2003              |         |        | 2       | 3        | 2       | 7     |
| 2004              | 1       | 2      | 2       | 1        | 2       | 8     |
| 2005              | 2       | 4      | 1       | 4        | 0       | 11    |
| 2006              | 2       | 1      | 0       | 5        | 0       | 8     |
| 2007              | 2       | 2      | 1       | 5        | 1       | 11    |
| 2008              | 0       | 2      | 0       | 3        | 3       | 8     |
| 2009              | 0       | 3      | 0       | 1        | 1       | 5     |
| 2010              | 2       | 3      | 1       | 0        | 0       | 6     |
|                   |         |        |         |          |         |       |
| <b>CAPD</b>       |         |        |         |          |         |       |
| 2003              | 0       | 0      | 0       | 0        | 0       | 0     |
| 2004              | 0       | 0      | 0       | 1        | 0       | 1     |
| 2005              | 0       | 0      | 0       | 1        | 0       | 1     |
| 2006              | 0       | 0      | 0       | 0        | 1       | 1     |
| 2007              | 0       | 0      | 0       | 0        | 1       | 1     |
| 2008              | 0       | 0      | 0       | 0        | 0       | 0     |
| 2009              | 0       | 0      | 0       | 0        | 0       | 0     |
| 2010              | 0       | 0      | 0       | 0        | 0       | 0     |
|                   |         |        |         |          |         |       |
| <b>Transplant</b> |         |        |         |          |         |       |
| 2003              | 0       | 2      | 9       | 14       | 16      | 41    |
| 2004              | 0       | 1      | 8       | 13       | 12      | 34    |
| 2005              | 0       | 1      | 5       | 13       | 15      | 34    |
| 2006              | 0       | 3      | 6       | 16       | 14      | 39    |
| 2007              | 0       | 3      | 3       | 17       | 12      | 35    |
| 2008              | 0       | 5      | 5       | 16       | 9       | 35    |
| 2009              | 0       | 6      | 6       | 17       | 15      | 44    |
| 2010              | 0       | 6      | 10      | 12       | 17      | 45    |

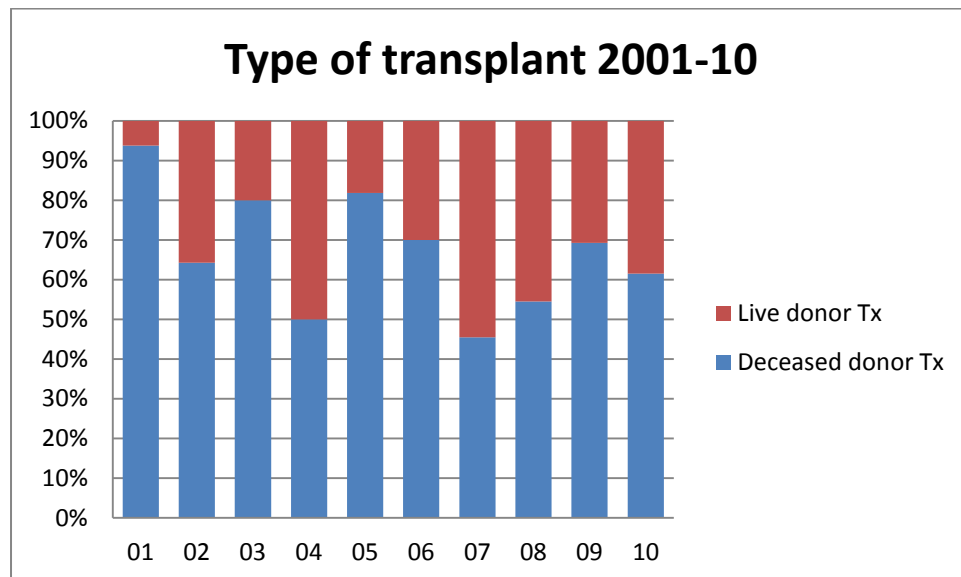
In the past 9 years between Jan 2001 and Jan 2011 there were 127 transplants including 39 live donor and 88 deceased donor transplants with 6 graft failures within the first year to date. There were no graft failures in the first year in 2010.

Fig 6.4.6 Type of transplant

|                                   | 2001      | 2002      | 2003      | 2004     | 2005      | 2006      | 2007      | 2008      | 2009      | 2010      |
|-----------------------------------|-----------|-----------|-----------|----------|-----------|-----------|-----------|-----------|-----------|-----------|
| LRD 1st Tx                        | 1         | 4         | 3         | 3        | 2         | 3         | 6         | 5         | 4         | 5         |
| LRD subsequent Tx                 |           | 1         | 1         | 1        | 0         |           | 0         | 0         | 0         | 0         |
| Deceased donor 1 <sup>st</sup> Tx | 12        | 9         | 14        | 4        | 9         | 6         | 4         | 4         | 9         | 6         |
| Deceased donor 2 <sup>nd</sup> Tx | 3         |           | 2         | 0        |           | 1         | 1         | 2         | 0         | 2         |
| <b>TOTAL</b>                      | <b>16</b> | <b>14</b> | <b>20</b> | <b>8</b> | <b>11</b> | <b>10</b> | <b>11</b> | <b>11</b> | <b>13</b> | <b>13</b> |
| DCD*                              |           |           |           |          |           | <b>1</b>  | <b>1</b>  | <b>0</b>  | <b>0</b>  | <b>1</b>  |
| Pre-emptive LRD                   |           | 1         | 2         | 3        | 0         | 2         | 3         | 1         | 2         | 3         |
| Pre-emptive DD                    | 1         | 1         | 3         | 1        | 2         | 2         | 1         | 2         | 1         | 2         |

\*DCD- donation after cardiac death

Fig 6.4.7 Live related transplant v decease donor transplant



Over the past 4 years the LRD transplant rate has been 41.6%. This compares favourably with the national rate of 36.5% (12<sup>th</sup> UK Renal Registry Annual report 2009).

Fig 6.4.8

**Survival rates for paediatric age (<18 years) transplant patients<sup>1</sup>. NHSBT data**  
 (Note: only the risk adjusted rates for a centre can be compared validly with “all centre” rates)

|                                 |                      | Bristol      |                   |        |                   |        | All centres  |                   |        |
|---------------------------------|----------------------|--------------|-------------------|--------|-------------------|--------|--------------|-------------------|--------|
|                                 |                      | Unadjusted   |                   |        | Risk adjusted     |        |              |                   |        |
| First deceased donor transplant |                      | Number of Tx | Survival estimate | 95%CI  | Survival estimate | 95%CI  | Number of Tx | Survival estimate | 95%CI  |
| 1 yr survival                   | Graft                | 32           | 97                | 80-100 | 97                | 84-100 | 315          | 94                | 90-96  |
|                                 | Patient              | 32           | 100               | N/A    | 100               | N/A    | 315          | 99                | 97-100 |
| 5yr survival                    | Graft                | 48           | 83                | 69-91  | 82                | 65-92  | 354          | 81                | 77-85  |
|                                 | Patient              | 48           | 98                | 86-100 | 97                | 85-100 | 355          | 99                | 97-100 |
| <b>Live donor transplants</b>   |                      |              |                   |        |                   |        |              |                   |        |
| 1 yr survival                   | Graft                | 20           | 85                | 60-95  | 89                | 68-98  | 273          | 97                | 94-98  |
|                                 | Patient <sup>2</sup> | 20           | 95                | 69-99  | 96                | 79-100 | 262          | 99                | 97-100 |
| 5 yr survival                   | Graft                | 17           | 88                | 61-97  | 89                | 61-99  | 213          | 91                | 86-94  |
|                                 | Patient <sup>2</sup> | 14           | 100               | N/A    | 100               | N/A    | 194          | 97                | 94-99  |

<sup>1</sup>Cohorts for survival estimation

1 year survival 1 Jan 2005 -31 Dec 2009

5 year survival 1 Jan 2001-31Dec 2005

<sup>2</sup> First grafts only –re-grafts excluded for patient survival estimation

**e) Chronic kidney disease (non dialysis/transplant)**

2010-11

There were 35 admissions in 15 patients occupying 214 bed-days. Seven of these admissions were in 1 patient with CKD post Wilm’s tumour and associated with hypertension secondary to renal artery stenosis

# NEPHROLOGY

## 7.1 DURATION OF ADMISSION

|                        | 2006/7 | 2007/8 | 2008/9 | 2009/10 | 2010/11 |
|------------------------|--------|--------|--------|---------|---------|
| Number of admissions   | 48     | 73     | 69     | 68      | 75      |
| Number of patients     | 37     | 46     | 47     | 39      | 42      |
| Bed days               | 216    | 588    | 436    | 336     | 459     |
| Length of stay- Median | 2      | 4      | 3      | 3       | 3       |
| Mean                   | 4.5    | 8      | 6.3    | 8.6     | 6.1     |
| Range                  | 1-23   | 1-47   | 1-35   | 1-20    | 1-75    |

In 2010-11 there were 2 patients with arthrogryposis, renal dysfunction and cholestasis (ARC) syndrome, a rare multi-system genetic disorder, who had multiple admissions accounting for 9 admissions and for 176 bed days. Another boy with complex urological problems had 11 admissions and 59 bed days. Together these 3 patients accounted for 51% of the general nephrology bed days

## 7.2 AGES OF ADMISSIONS

|       | 2006/7 | 2007/8 | 2008/9 | 2009/10 | 2010/11 |
|-------|--------|--------|--------|---------|---------|
| < 1   | 3      | 29     | 6      | 15      | 31      |
| 1-6   | 11     | 17     | 18     | 19      | 14      |
| >6-12 | 20     | 17     | 19     | 18      | 12      |
| >12   | 14     | 10     | 26     | 16      | 18      |

## 7.3 SOURCE OF ADMISSION

Fig 7.3.1: Area of admission for children with general nephrology problems

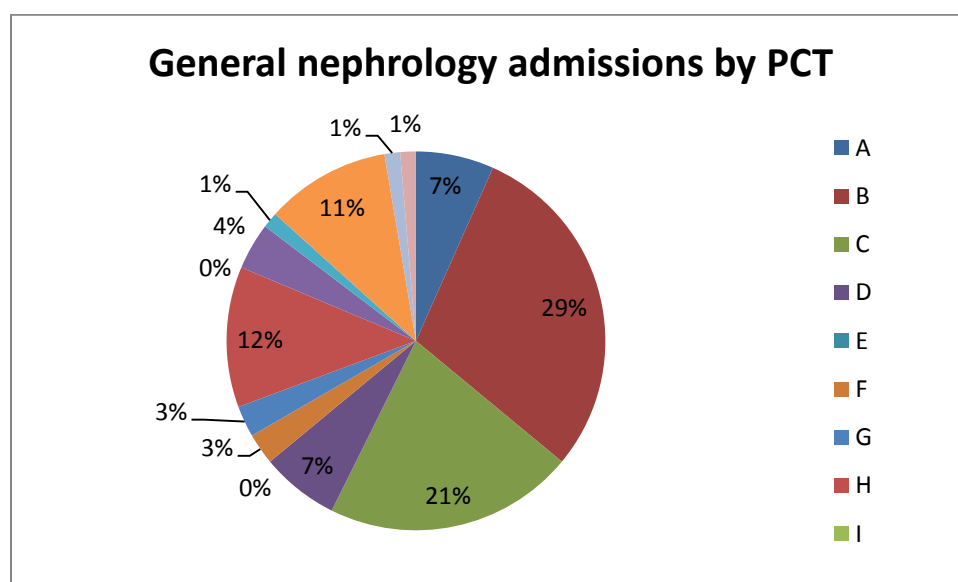


Fig 7.3.1 A Admission by DGH 2008-11

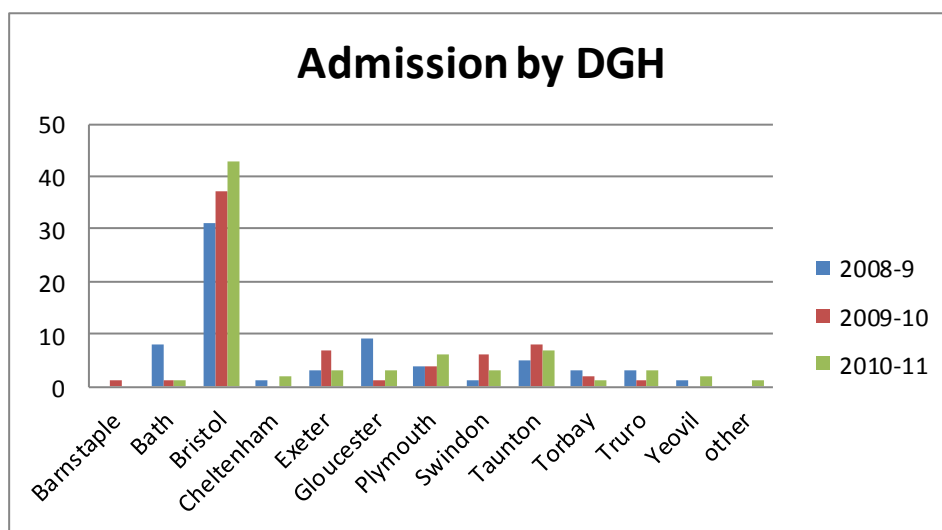
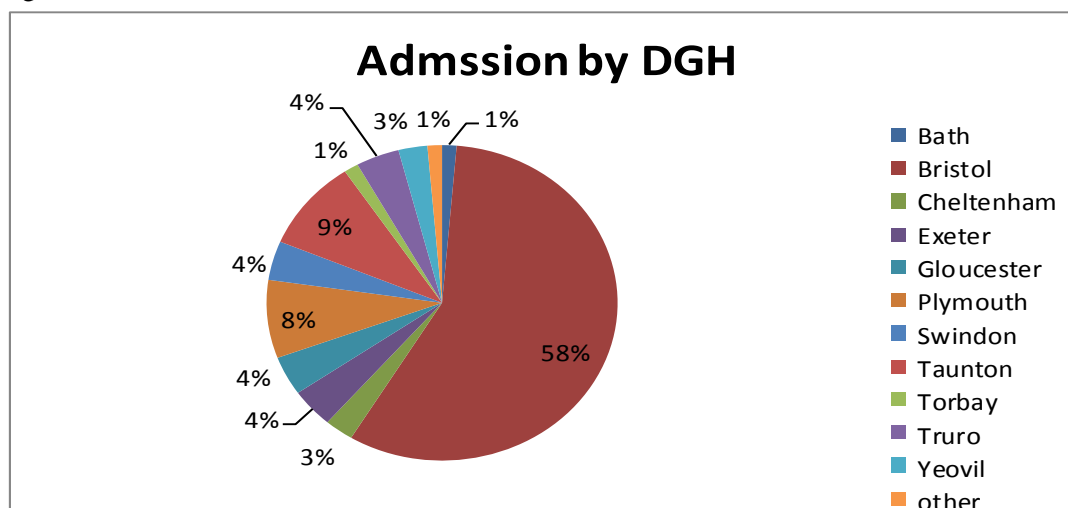


Fig 7.3.1 B 2010-11



#### 7.4 REASON FOR ADMISSION

Patient's admissions are categorised into emergency, planned and semi-planned (this would for example include a biopsy that needed to be done within a few days rather than on the next planned list)

Fig 7.4.1

|              | 2006-7              | 2007-8              | 2008-9              | 2009-10             | 2010-11             |
|--------------|---------------------|---------------------|---------------------|---------------------|---------------------|
|              | Number of cases (%) | Number of cases (%) | Number of cases (%) | Number of cases (%) | Number of cases (%) |
| Emergency    | 20 (43)             | 49 (67)             | 43(62.3)            | 51(75)              | 57(76)              |
| Planned      | 27( 57)             | 24 (33)             | 22(31.8)            | 17(25)              | 16(21)              |
| Semi planned | 1(2)                | 0                   | 4(5.7)              | 0                   | 2(3)                |

As in previous years the vast majority of nephrology admissions were emergencies, with only 21% being planned admissions.

Reason for admission in general nephrology patients-main reason for admission

Fig 7.4.2

|       | NS New (non-biopsy) | NS old | SLE | HSP | UTI | Nephritis | Renal Bx | BP | cystinosis | Sur/invest | Other |
|-------|---------------------|--------|-----|-----|-----|-----------|----------|----|------------|------------|-------|
| 06/7  | 0                   | 3      | 1   | 3   | 2   | 2         | 23       | 5  | 0          | 5          | 4     |
| 07/8  | 4                   | 8      | 0   | 0   | 8   | 1         | 18       | 2  | 14         | 2          | 16    |
| 08/9  | 3                   | 5      |     |     | 2   | 2         | 22       | 4  | 9          | 5          | 17    |
| 09/10 | 0                   | 4      | 0   | 0   | 12  |           | 13       | 4  | 15         | 4          | 11    |
| 10/11 | 2                   | 5      | 1   | 6   | 10  | 0         | 17       | 2  | 0          | 12         | 20    |

Fig 7.4.3 RENAL BIOPSY-NON TRANSPLANT

|       | No adms | No patients | HSP | Protein+/- Haematuria | FSGS | SRNS | NS other | SLE | other |
|-------|---------|-------------|-----|-----------------------|------|------|----------|-----|-------|
| 06/7  | 23      | 21          | 7   | 4                     | 3    | 5    | 4        |     |       |
| 07/8  | 18      | 18          | 2   | 5                     | 1    | 4    | 6        |     |       |
| 08/9  | 23      | 22          | 6   | 4                     | 0    | 7    | 3        | 1   | 2     |
| 09/10 | 13      | 13          | 6   | 4                     |      | 1    | 1        |     | 1     |
| 10/11 | 22      | 22          | 9   | 4                     | 0    | 1    | 5        | 2   | 1     |

In 2010/11 there were 22 admissions in 21 children specifically for renal biopsy, 5 of these were day cases and not included in previous data. There were an additional 16 biopsies in seven children who had undergone renal transplants, 2 of which were in the primary admission.

Fig 7.4.4: Numbers of renal biopsies

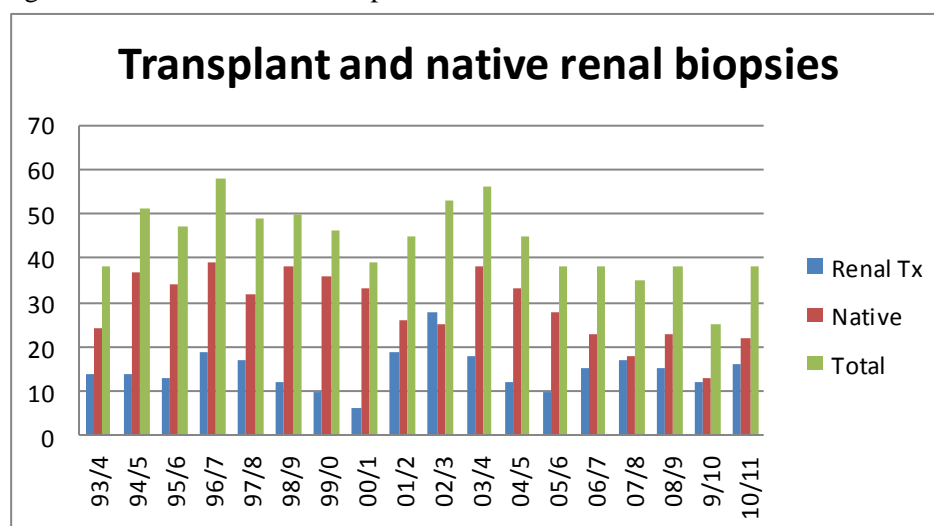


Fig 7.4.5 Indications for biopsy

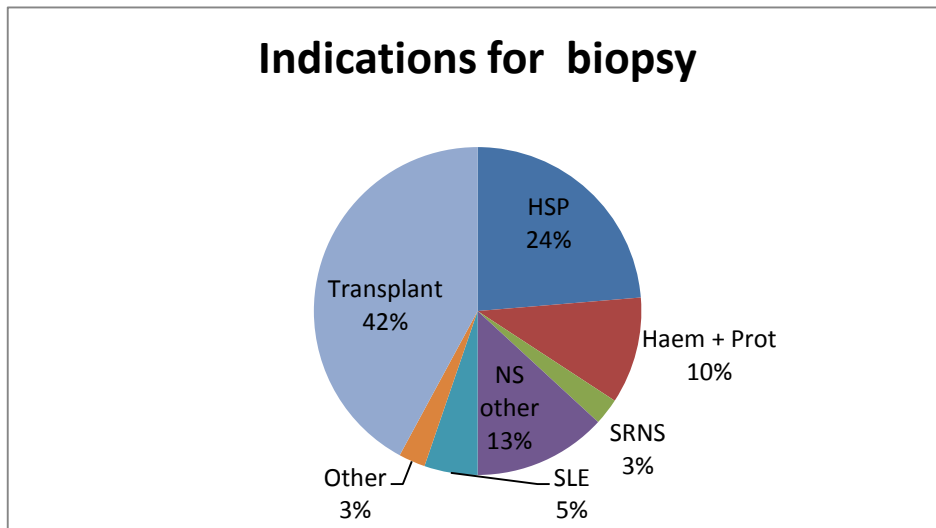
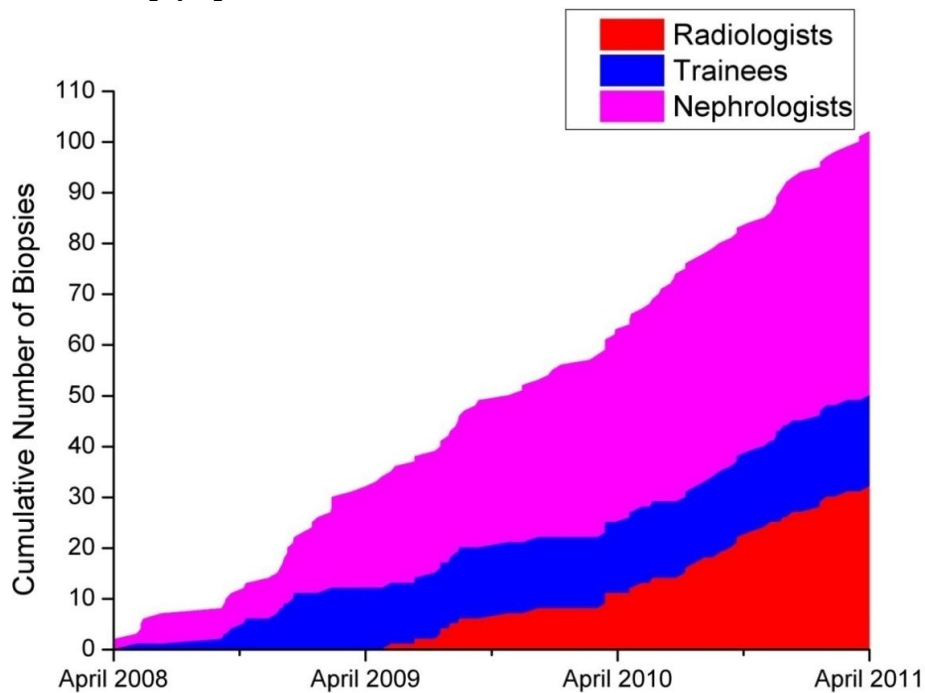


Fig 7.4.6 Renal biopsy operator



Renal biopsies are all performed with real-time ultrasound as guidance. Over the past 3 years the paediatric radiologists have increasingly contributed to the renal biopsy service and we are very grateful to them for this

## 8. OTHER ACTIVITIES OF THE CHILDREN'S RENAL UNIT

### 8.1 PAEDIATRIC UROLOGY

Since the move to the Children's Hospital, patients with routine urological problems are admitted to the surgical wards. Those children admitted to the renal unit are generally those with urological problems complicated by significant renal disease. There are some patients admitted for surgery with pure urological problems including patients for circumcision and hypospadias repair.

The liaison between the urologists and nephrologists continues with a weekly combined nephro-urological radiology meeting. In addition there is a three monthly meeting to discuss all the paediatric urodynamic investigations performed. One of our paediatric urologists also now attends the regular transplant clinics to provide support and specific urological input. Since 2010 a number of scheduled theatre slots have been set aside for live-related donor transplants in complex patients where both a transplant surgeon and a paediatric urologist will be available.

The laparoscopic service continues to develop, with the majority being discharged within 24h. Further laparoscopic procedures have also been developed including laparoscopic pyeloplasty.

### 8.2 SURGERY

Close links with the department of paediatric surgery has been integral to the smooth running of our department. The paediatric surgical team are responsible for all our access procedures except for fistulae which are performed by vascular surgeons. Many of our infants require gastrostomy and sometimes fundoplication. The paediatric surgeons also assist in some of the intra-abdominal transplants when there has been major surgery beforehand. In addition one of the transplant surgeons undertakes parathyroidectomy when required.

### 8.3 OUTPATIENT CLINICS

The following clinics are held regularly

#### **BRHC**

Complex nephrology clinics attended by the full multi-disciplinary team 3-4 per week

General nephrology 1 per week

Vasculitis clinic, pre-transplant assessment clinic and joint nephrology / endocrine clinics each 3 monthly

Nurse led follow up clinic twice weekly

#### **Southmead Hospital**

Transition clinic 3 monthly

Dr McGraw and Dr C Dudley (adult nephrologist at SMH)

General nephrology fortnightly clinic

Dr McGraw, Dr Inward and Dr Coward

#### **Outreach clinics**

Truro 3 full days per annum

Professor Saleem

Plymouth 3 full days per annum

Dr McGraw

Exeter 4 full days per annum

Dr Inward

Barnstaple 2 full days per annum

Professor Saleem

Torbay 2 half days per annum

Dr McGraw

Taunton 3 full days per annum

Dr Tizard

Yeovil 2 full days per annum

Dr McGraw

Bath 4 full days per annum

Dr Tizard

Swindon 4 3/4 days per annum

Dr Tizard

Gloucester 3 full days per annum

Dr Dudley

Cheltenham 3 full days per annum

Dr Dudley

Half day clinics are sometimes extended to full days and ad hoc clinics are undertaken when needed

| Clinic                       | 2010-11 |           | Total 2010-11 |
|------------------------------|---------|-----------|---------------|
|                              | New     | Follow up |               |
| BCH CRF/complex clinic       | 17      | 715       | 732           |
| BCH general nephrology       | 132     | 217       | 349           |
| Endocrine                    | 3       | 32        | 35            |
| Transplant pre-assessment    | 3       | 15        | 18            |
| Transplant assessment clinic | 0       | 22        | 22            |
| SMH Transition               | 16      |           | 16            |
| SMH General                  | 91      | 186       | 277           |
| Barnstaple                   | 3       | 31        | 34            |
| Bath                         | 0       | 58        | 58            |
| Cheltenham                   | 3       | 31        | 34            |
| Exeter                       | 10      | 54        | 64            |
| Gloucester                   | 1       | 29        | 30            |
| Plymouth                     | 3       | 26        | 29            |
| Swindon                      | 7       | 48        | 55            |
| Taunton *                    | 3       | 27        | 30            |
| Torbay                       | 3       | 10        | 13            |
| Truro                        | 4       | 51        | 55            |
| Yeovil                       | 1       | 15        | 16            |
| Vasculitis                   | 7       | 13        | 20            |

\*1 clinic cancelled due to sickness

## 8.4 WARD NURSING

During the period of 2010 to 2011 the renal unit has seen some changes to the nursing team. These have included the secondment of a charge nurse to cover the ward sister during maternity leave, a senior staff nurse and nursing assistant leaving and the recruitment of 2 new staff nurses and 1 nursing assistant. Despite these changes the nursing team have continued to provide an excellent service with high standards of care.

Our Community Sister has been successful in securing a role within North Bristol NHS Trust working with a new team dedicated to the transition of patients from paediatric to adult services. This has meant halving her hours to take on this 18 month contract. The secondment of a ward nurse into community has helped reduce the pressure of losing the Community Sister for this time. This secondment from the ward will be offered every 6 months to another ward nurse.

During the summer of 2010 a nurse went on a secondment to a very busy medical ward for 6 months. The secondment gave the nurse the opportunity to experience a wide range of general medical conditions as well as learn new skills and develop existing ones. The ongoing secondment of staff to the renal unit helps to raise the profile of renal nursing, as well as providing support for those patients who on occasions find themselves admitted to other ward areas.

Nurse rotations into haemodialysis continue and to date we now have 11 competent haemodialysis trained nurses, with another nurse undergoing training. We currently offer an on call service for dialysis on Sundays.

Non-medical prescribing continues and the Community Sister has reviewed all heparin and Alteplase use in Haemodialysis. The management of anaemia in the renal patients has also been taken on in this role.

Three members of staff from the renal unit have developed a paediatric renal study day and the University of the West of England has agreed to take this study day on as a paediatric master class alongside their adult based renal course in the future.

Continued training has been high on the agenda and in 2011 three nurses will attend the acutely ill child module at the university, 1 nurse will attend the child protection module and 2 nurses are undergoing student mentor and assessing training. The ward has seen an increase in student nurse numbers and at times has had as many as 5 students on the ward. Although very small, the ward has been able to offer an excellent learning package for the students which has included time in the haemodialysis unit, attending theatre to observe kidney transplants and spending time with the community team.

### Plans for the forthcoming year:

- Continued secondment of nursing staff to the haemodialysis and community every 6 months
- Secondment of a ward nurse to another ward within the children's hospital
- Encourage development of the nursing team by obtaining funding for external courses such as the acutely ill child, renal course and teaching and assessing
- The development of both senior and junior nursing staff
- Nurse prescribing to continue and expand in use
- Renal study day to be held
- Renal study day to then be linked in with University of the West of England adult renal course as a paediatric master class.

## 8.5 COMMUNITY NURSE SERVICE

The community nursing service has continued to flourish in the last year to complement hospital based care. The aim of the service has always been to provide safe high quality care for children with chronic/end stage renal failure in or as near to the family home as possible. Due to the large geographical area this has at times been difficult to maintain but we have strong links and joint working with local children community nursing teams and paediatric units.

The Bristol based team is still responsible for education, training, planning and evaluation of the care provided in the community for children with renal failure but working closely with local teams so that generic skills support and some specific renal procedures can be provided locally. This has been of enormous benefit to the child and family and as recommended by the National Service Framework for Children and Young People (DH 2004) the service is bridging the gap between hospital and home, maintaining the chronically sick child where possible within their local community.

To maintain and establish these links has required considerable liaison and training by the Bristol based team.

Using local teams has benefited the child and family and has reduced hospital admission for them, but the intense community workload has not decreased. During this period there has been between 6-10 patients on peritoneal dialysis. The challenges of caring for many younger children on peritoneal dialysis has encouraged the team to review all peritoneal dialysis procedures, and working with the ward ensuring that hospital based peritoneal dialysis and home dialysis are following the same pathway.

In the past 2 years all members of nursing team have been responsible or active in following key areas for development.

Anne Johnston : Peritoneal Dialysis.

- Development of multidisciplinary dialysis pathway
- Revision of pre dialysis education.
- Working with ward staff on uniformity of dialysis procedures
- Dialysis in-house study day
- Three monthly adequates and PET test if possible.
- Revision of procedure for vascaths in the home

Liz Griffiths : Transplantation.

- Revised patient and family transplant information
- Use of DVD
- Structured approach to transplant preparation working with multi disciplinary team
- Revision of transplant pathway
- Increased follow up for long term patients, three times within first year and annually thereafter.
- Working closely with transplant coordinators.

Jo Woodland: Transition.

- Revising transition pathway with multi-disciplinary team

Working with young people and adult services to ensure our transition programme meets the needs of young people.

- Establishing and strengthening points of transfer to adult services across the region.
- Secondment to NHS Kidney care supporting young adult project.

Current staffing for the team is 1 full time band 7 and 1.4 band 6 nurses. Jo Woodland (full-time band 7) is seconded for 18 months to NHS kidney care for 0.5 WTE. To cover these hours the rotation post from the ward has continued. This has been extremely successful, and has provided a development opportunity for ward based nurses and has provided the community team valuable support and strengthens links with ward staff.

Staffing has remained an issue for the whole unit, especially the demands on an over stretched haemodialysis service. The community nurses have all been trained in haemodialysis and on average work 2-3 shifts per month on the haemodialysis rota. This has had enormous benefits in all areas, the community staff have increased their skill base, we have boosted the number of the haemodialysis team, and this has enabled the community nurses to spend time within haemodialysis and can act as bridge between hospital and home.

In the last three years the community team have been auditing dialysis access, which has been reviewed with clinicians and nursing teams. The results of this audit have influenced changes and development in clinical practise.

In the last year there has been a change to our supply of erythropoietin injections. This has resulted in a change of practise to a longer acting medication which has required increased monitoring of haemoglobins. The community team monitors haemoglobin levels of patients receiving erythropoietin treatment and coordinates clinical monitoring.

Jo woodland has presented the transition pathway at the Annual Paediatric nephrology nursing conference in Dublin and has also completed the non medical prescribing course.

The community team does not work in isolation, for as well as working closely with all staff members on ward 37 some community work is done with other members of the multi-disciplinary team. Joint visiting with the social work, psychology, play specialist and dietetic team are a regular occurrence which provides a higher quality service for the family and help ensure that communication lines between all members of the team are effective and open.

The nurse led clinic service has been well utilised this year on both a Monday and Wednesday.

- Supporting young adult project

The supporting young adult project is one of five projects developed nationally by NHS Kidney Care.

Between the ages of 14-25 all young adults often face a difficult time, socially and educationally, face big changes and need to make important decisions. When this is complicated by having a long term medical condition this transition can be a stressful time.

The young adult project in the south west employed two part time coordinators, Sally Tutton and Jo Woodland. The project started Jan 2011 with the aim of providing sustainable service development for young adults with kidney disease across south west. The project is working with the children's hospital and the 5 adult renal centres based within the southwest.

For the first 6 months of the projects the aims/achievements have been.

- Establish cohort.
- Work with units to build on existing services
- Engage young people as the 'voice' of the service
- Develop pathways of care for young people.

- Work with other agencies voluntary /social care/education.
- Identify link people within each area.
- Collections of quantitative and qualitative data to support the project.
- An anonymous survey to all young people with CKD4,CKD 5 and post-transplant between 14-25 in southwest
- Baseline self-assessment framework around transition/transfer and provision of service for young people in all units.

Over the next year the project will be collecting survey data, and working with teams on building a pathway of care for young people. Young adult clinics are being developed in adult centres/resources packs developed and peer support methods established. The project will be exploring the use of social media and web based methods to support this.

## 8.6 CLINICAL PSYCHOLOGY SERVICES

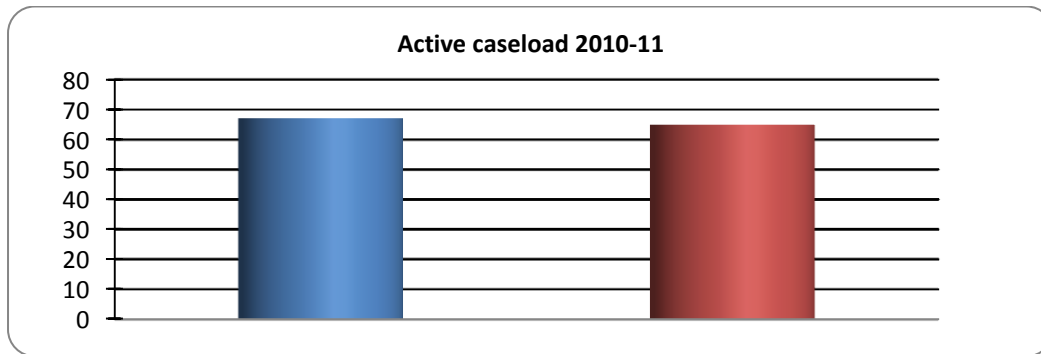
The Renal Unit continues to receive 0.8 WTE Clinical Psychology sessions (skill mixed with 0.6 WTE Highly Specialist and 0.2 WTE Consultant Clinical Psychologist sessions). The services to the paediatric renal team encompass direct work with children, young people and families, joint working with other members of the multi-professional team, consultation, support to service developments and increasing the psychological skills and knowledge throughout the team.

### 8.6.1. Direct clinical work

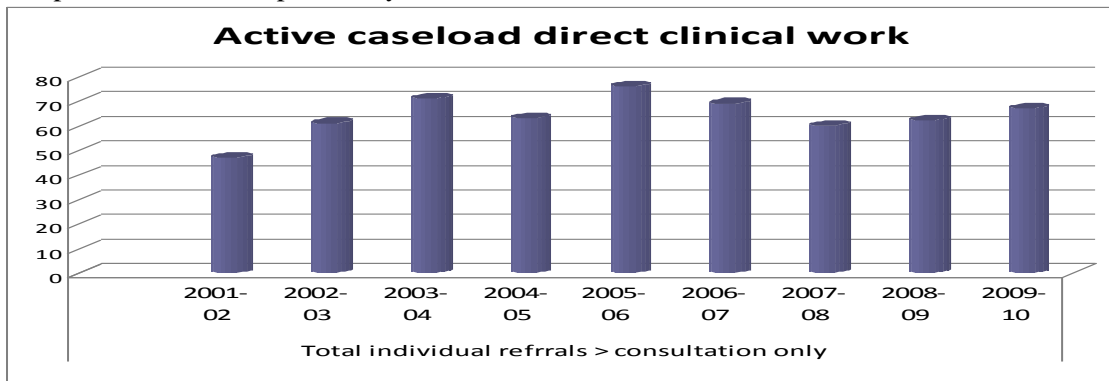
In 2010-11, 65 patients and their families were seen for specialist and targeted direct clinical work with children, young people and families. Comparisons with previous years with regard to direct, face to face clinical work undertaken is summarised below. This data excludes travel time to regional home visits and brief consultations lasting less than 30 minutes which occur regularly both on the ward and in the renal outpatient clinic. The only significant change this year is a relative increase in day patient hours which are explained predominantly by individual work with four teenage patients on haemodialysis and plasmapheresis.

Targeted work is undertaken primarily via the dialysis, transplant and transition preparation programmes with integrated assessments identifying the need for further specialist psychological assessment and intervention. The range of direct contacts per referral has been from a single contact of 1-2 hours duration (for example an annual transition interview with a community nurse who follows up the support and interventions identified) to multiple contacts for therapy work (e.g. specialist assessment and intervention with newly diagnosed infants with complex needs, end stage renal failure potentially requiring palliative care, a young person with learning difficulties and challenging behaviour in end stage renal failure and a population of vulnerable young people with serious issues of non-compliance complicated by learning difficulties or challenging behaviours).

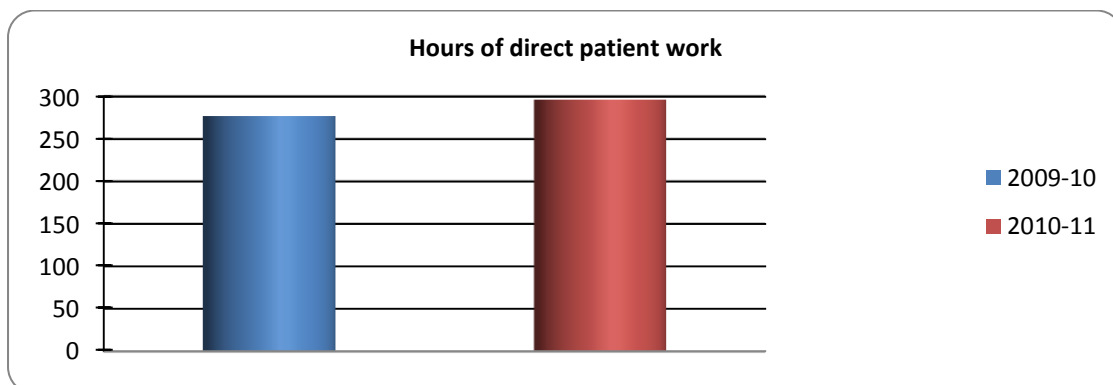
1. Total number of referrals accepted for face to face direct work:

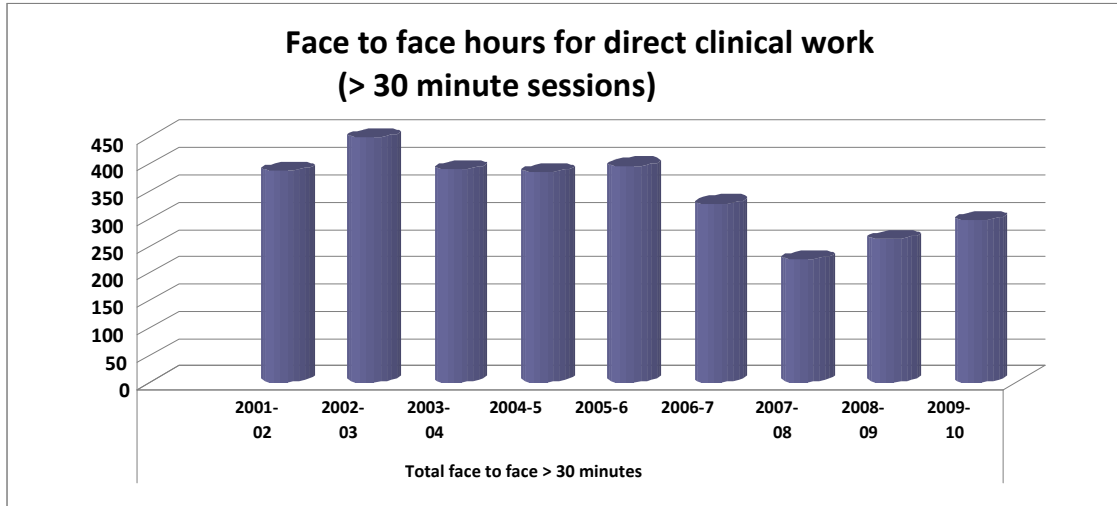


Compared to data from previous years:

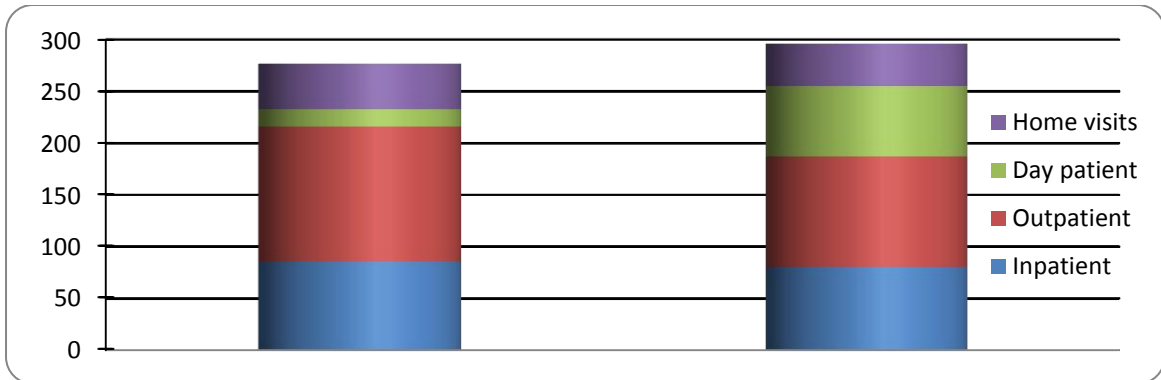


2. Face to face hours of direct patient work (sessions > 30 minutes)

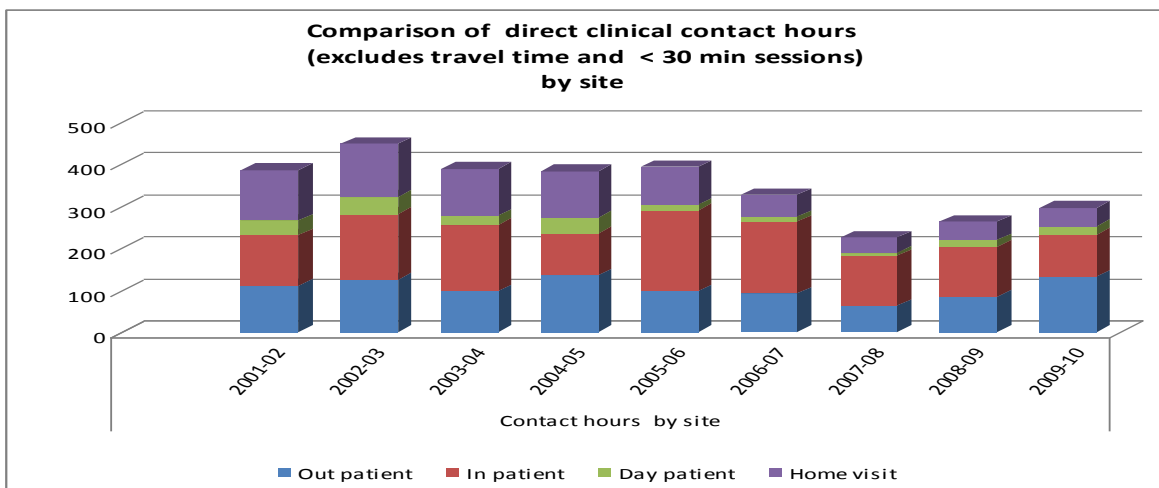




3. Comparison of direct clinical work by site:



Compared to data from previous years:



The age range of referrals has been from neonates to eighteen year olds. The psychological assessments and interventions which have been provided are summarised below:

- Assessing the child/young person's health beliefs and understanding of their illness and advising on developmentally appropriate interventions to decrease anxiety and trauma and promote concordance, informed consent and the 'expert patient' self-management model for young people, particularly within the Transition Programme and the Transplant Programme
- Assessing parental health beliefs and understanding of their child's illness to enable the team to provide informational and emotional counseling concordantly and empower parents as partners as part of their psychological adjustment to their child's diagnosis
- Supporting parents, children and young people to problem solve and adapt to the impact of the illness (acute renal failure presentations as well as chronic and established renal failure)
- Management of procedural and generalised anxiety and condition-related depression
- Management of emotional and behavioural difficulties secondary to or exacerbated by the renal illness with referral for shared care with local Specialist Child and Adolescent Mental Health Services when severe, complex and/or systemic mental health issues were identified (e.g. when a specialist eating disorders clinic, psychiatric assessment or family therapy clinic is indicated)
- Developmental assessments of babies developing end stage renal failure in their first year to ensure early identification of any delay or disorders for informed referral to local Community Child Health and Disability Services and learning through play advice for parents, hospital play specialist and nurses.
- Cognitive assessments when indicated (e.g. capacity for informed consent, independent condition management)
- Supporting the maintenance of normal developmental trajectories in adolescence, particularly in relation to individuation, identity-formation and separation through the transition programme assessments and action plans
- Palliative, end of life care and bereavement support

#### 8.6.2 Consultation and joint working:

The clinical psychologists regularly undertake joint assessments, interventions and supervised working with other members of the team e.g. play specialists, community nurses, social worker, haemodialysis and ward nurses in all the areas of direct face to face work described above. Consultation and liaison is formally undertaken within the weekly multi-professional grand round and the weekly integrated care meeting. This ensures equality of access to psychological advice for all children, young people and their families in the care of the renal team. Once a month, the integrated care meeting is used to review all children and young people on or about to enter the transplant pathway. The remaining integrated care meetings each month are utilised for targeted consultation for children and young people identified by the team as having complex medical, psychological and social needs which need an integrated multi-disciplinary discussion.

Monthly Community Renal Team Liaison and Transition Programme meetings are coordinated by the clinical psychologists and Renal Social Worker to enable requests for

specialist psychological assessments /interventions to be made, case consultation to be offered and co-ordinated care to be organised.

Consultation and clinical supervision in relation to individual case management is offered as appropriate. A reflective practice and staff support session is regularly available to ward staff.

Liaison continues to be undertaken with Child and Adolescent Mental Health Services, Child Health Services, Children and Young People's Services and voluntary sector services locally and throughout the region covered by the renal services as needed to ensure continuity of care and access to local services when appropriate.

#### 8.6.3 Team and service development activities:

The consultant psychologist attends the bi-monthly team issues meeting to provide psychological advice with regard to developing the renal team and the services offered. In addition to this, ongoing service improvement activity has been undertaken with other members of the multi-professional team in relation to the dialysis and transplant pathways, end of life care planning and transition.

The changes made to the transition programme in 2010 have improved the efficiency of the service offered to young people with regard to appropriately targeting the psychologist and social worker for the most complex cases using a stepped approach with 3 levels on the programme. Improved information resources for young people have been developed and are currently being piloted. Over the last year the renal replacement therapy preparation programme has been reviewed and developed in order to ensure young people and carers are able to make informed decisions in partnership with the team based on psychologically informed assessment and preparation.

#### 8.6.4 Objectives for 2011-12

- Maintain equitable, needs led access for targeted direct patient work balanced with indirect work through consultation and teaching
- Review the use of co-ordinated psychology, SALT and dietetics services with regard to promotion of feeding in vulnerable
- Participate in the Kidney Care regional Supporting Young Adults project to further review and develop work on the Transition pathway and processes
- Explore participation in multi-centre research study on concordance in young people
- Complete retrospective renal transplant preparation package evaluation and develop prospective integrated outcome measures

### 8.7 DIETETIC REPORT

The service continues to be funded to 1.0wte which is split into a skill mix of a specialist post and a paediatric rotational post. This skill mix continues to support renal dietetic training of junior staff within the department and has improved recruitment and retention of staff within the department.

The dietitians provide a service to Inpatients and Outpatients with renal disease across the region. This includes weekly clinics, quarterly growth clinics and home visits where possible.

Geographical restraints mean patients cannot always be seen by a renal specialist dietician, so in this scenario, support is offered to the patient's local dietician to enable dietetic care closer to home.

This has been particularly successful in our most distant regions. We are currently planning a project which will enable us to offer more support to general paediatric colleagues in hospitals in the South West. We are awaiting the final details but have been successful in our grant application to the British Kidney Patients Association, which will fund this training and resource package.

The dietitians are members of the Paediatric Renal Nutrition Interest Group (PRING) and the Renal Nutrition Group of the BDA (RNG). Local micronutrient guidelines have also been completed for children undergoing RRT and are used frequently by the dietitians, as is a comprehensive low potassium regional dietsheet, produced in collaboration with colleagues in Southampton and UHWales. This receives very positive feedback from patients and their carers. New dietetic resources are currently being produced with patient/user involvement. In addition, we have completed Guidelines for Monitoring Growth in Infants and Children with CKD, together with the endocrinology team at BRCH. The document has recently been put forward for approval from BAPN, BSPED and PRING, aiming to be used nationally. A mini audit of BRCH practice against these guidelines was also completed.

The specialist postholder has also been involved, as a representative of PRING, in a working party with members of BAPN, RCPCH and NHS Kidney Care to produce guidelines for the development of Paediatric Nephrology Networks across the UK

Aims for the next year are to:-

- Implement growth monitoring standards at BRCH and across the south-west region and audit practice at BRCH
- Develop and plan a training package in basic paediatric renal dietetics for our region
- Further support local paediatric dietetic colleagues in the Southwest in provision of shared patient care
- Continue to improve patient and staff nutrition education resources
- Continue to work on developing good working relationships with psychology colleagues around re-establishing good feeding practices
- Develop closer working relationships with speech therapy colleagues regarding feeding practices

## 8.8 PHARMACISTS' REPORT

The service is funded for 0.5 WTE band 7 pharmacist, which covers the inpatient section of the renal patient population. This is most likely to be a pharmacist with a minimum of 2 years' experience post qualification and may or may not have previous paediatric or renal experience. The pharmacist is a member of the Neonatal and Paediatric Pharmacists Group (NPPG) and the Renal Pharmacy Association.

The overarching role of the pharmacist within the renal team is to promote safe and effective use of medicines. This service is provided in a variety of different ways:

- Checking that patients are prescribed the appropriate medications on admission, during inpatient stay and on discharge from hospital.
- Working with the medical team to facilitate timely discharge from hospital and avoid unnecessary delays (e.g. waiting for medications).
- Working with the nursing team to ensure they are confident in giving medications, especially when complex calculations or unusual/unlicensed drugs are involved.
- Working with the multi-disciplinary team to ensure any other patient needs regarding medications are met e.g. problems with getting medicines from local pharmacies, problems remembering to take medicines, providing written information about drug side effects etc.
- Working with the multi-disciplinary teams across the region to avoid medicine related complications when transferring patients back to secondary care centres.
- Working with the multi-disciplinary team to formulate medicine related guidelines that promote safe and cost effective prescribing.
- The pharmacist is a core member of the clinical governance group which responds to incidents and works with all clinical ward staff to reduce risks in medicine prescribing, dispensing, storage and administration.

The pharmacist is also able to respond to changes in medication supplies from drug companies such as supply shortages or discontinuation of medications that the team use, in order to minimise any disruption to patient care.

Being part of a specialist team like the renal unit means the pharmacist can contribute to a variety of teaching sessions from regional study days for nurses, to international pharmacist conferences (NPPG 2011).

## 8.9 SOCIAL WORKER'S REPORT

The Children's Renal Unit has a social worker able to provide a dedicated service to children and young people with renal failure and their families. Our social worker is employed by Bristol City Council, but the post is fully funded by the Renal Unit.

The social worker is able to take an holistic approach in supporting children and young people with chronic or acute renal failure and their families. We know caring for a child or young person with chronic or acute health difficulties is likely to put pressure on family functioning as parents try to 'juggle' their lives to accommodate the needs of the child with kidney disease with the needs of the rest of the family.

With parental agreement, the social worker will meet with a family to discuss their particular circumstances, identify the needs of the child and carer and explore the impact of renal disease on other aspects of family life. The social worker can give advice and support on a range of personal, emotional and practical matters. For many families, issues arise relating to housing, employment, benefits and finances, education and other areas and practical advice

and support can be offered. The social worker is able to meet with families on the Ward, at outpatient clinics or by visiting the family home.

She will maintain regular contact with families to review changing needs throughout the different stages of chronic renal failure, particularly around the time of dialysis, transplant and transition to adult services.

The paediatric renal social worker provides a link to social workers in the community when they are involved with a family. In addition, she will contact locality social workers when appropriate, to request services and supports at a local level to meet the needs identified. She is also able to provide advice and support with safeguarding issues within the Team.

The paediatric renal social worker is also able to provide an advocacy role for parents and carers and ensure the wishes and feelings of the child or young person in relation to their care are heard.

As part of the multi-disciplinary paediatric renal team, the social worker works closely with other team members and attends weekly integrated care and clinical team meetings. Regular liaison with Cardiff colleagues continues to ensure that children, young people and their families from Wales attending the Unit in Bristol for transplant receive appropriate support.

She is actively involved in the British Association of Social Workers (BASW) Renal Special Interest Group networking with other specialist social workers around the country to maintain consistency and good practice.

The paediatric renal social worker was a member of the Implementation Group of the National Kidney Care Patient Transport Audit 2008 – 2010 aimed at improving transport services nationally for haemodialysis patients.

#### 8.10 PLAY SPECIALIST'S REPORT

The role of the Hospital Play Specialist (HPS) on the Renal Unit is a diverse one. We see patients that have varying needs. Acute cases initially maybe very unwell and require distraction from pain, or relaxation techniques. Children may need help with compliance in procedures or medicine taking and all children need normalising play to help them cope with the hospital experience. There are also long term patients that have had various admissions throughout their lives. These children still have the same needs as our acute patients but the play specialist may use play to help them to learn and to come to terms with their illness. The Play specialist can also help them carry out as normal a life as possible by making sure they engage in the kind of activities that are enjoyed by their age group outside of the hospital even if they have frequent admissions. Guidance is given to help them to act out their fears or resentment to certain procedures or treatments in a safe environment.

##### Ward play specialist

This year the play department has been looking specifically at our patients with complex needs and how we can improve their experiences in the hospital. This has been reflected with the work of the renal play specialist who has been putting together individual play plans for our children with complex needs thinking differently about the way they play. This year I have focussed on our younger children who are long term patients or on regular haemo/peritoneal dialysis ensuring appropriate play activities are provided to meet each child's needs. I aim to give them the opportunity to experience and explore a wide range of toys, games and activities to promote their skills in all areas of their development.

The playroom is now fully functioning with a wider range of toys and activities for children of all ages to access on the ward. I have liaised with other professionals who support our patients, sharing information about play plans and the children's progress. I have developed good relationships with families and provide play for siblings and emotional support for parents.

#### Community play specialist

This year I have expanded the community play specialist role by

- Preparing all ages as I feel that even our older patients would benefit from having individual input away from their parents and using less formal style to engage them.
- I have also adopted a mentoring role with some of our long term older patients
- I have also been following up some of the prep work with younger patients with support for hospital admissions.
- I have also have been working with the other members of the multi-disciplinary team looking at our transition program and how we prepare young people for their future health care needs.

#### 8.11 GOVERNANCE ISSUES-GUIDELINES, AUDIT AND PATIENT SAFETY

The paediatric nephrology team is committed to providing high quality care to patients and family but recognises the challenges of delivering this service.

A range governance of activities are undertaken to monitor quality of care and make improvements. A regular multi-professional team issues meeting is the forum for planning and reviewing these activities. There is a programme of guideline review and clinical audit in place. All members of the team are encouraged to report patient safety incidents via Ulysses, an electronic reporting system. A summary of the incidents reported related to care on Ward 37 this year is provided in this report.

Patients and families who have concerns or complaints are directed to the patients' advice and liaison service, now called LIAISE. Feedback from the LIASE service is provided for the clinical team and included below:

#### **Guidelines**

We currently have the following guidelines on our hospital intranet:

- Anaemia in Chronic Renal Failure
- Cyclophosphamide (Intravenous) Administration
- Hypertension - Investigation and Management
- Haematuria
- Henoch-Schönlein Purpura
- Hyperkalaemia
- Nephrotic Syndrome
- Nephrotic Syndrome: Steroid Resistant
- Peritoneal dialysis Catheter insertion for Chronic use
- Peritonitis management in children on chronic peritoneal dialysis
- Renal Biopsy - Organisation
- Renal Pathway in Children's Emergency Department
- Renal Stones

- Renal Transplant Protocol
- Steroid Resistant Nephrotic Syndrome
- Systemic Lupus Erythematosus Management Guidelines
- Urinary Tract Infection Guidelines
- Urinary Tract Infection: Referral Letter
- Vasculitis management in children
- Vitamin D Deficiency Management in Chronic Renal Insufficiency

Other guidelines under development:

- Haemolytic Uraemic Syndrome (HUS)
- Acute Kidney Injury
- Haemodialysis

## Audit

A summary of the clinical audit activity is shown below.

| Audit Project Status Report   |   |                       |
|---|---|-----------------------|
| 3.12.2011   | Carol Inward & Dan Speakman   | Paediatric Nephrology |
| Blood Transfusion Audit   |   |                       |
| Supervisor  | Carol Inward  |                       |
| Standards   | Trust Blood Transfusion Guidelines  |                       |
| Results: Pink forms hard to find – inconsistent filing. Completion of forms good. Informed consent not documented.  |   |                       |
|   |   |                       |
| Actions Taken   | Agreed forms to be filed in nursing notes. Information leaflets obtained. |                       |
| Results & recommendations regarding form redesign sent to chair of transfusion committee.   |   |                       |
|   |   |                       |
| Action Items  | Person Responsible  | Deadline              |
| Remind team about need to use information leaflets & document consent.  | CI & DS   | 1/4/11                |
| Re-audit  |   | 1/10/11               |
| MRSA Screening Audit  |   |                       |
| Supervisor  | Carol Inward  |                       |
| Standards   | Trust Infection Control Policy  |                       |
| Results: Policy not fully implemented. Regular screening of hamo patients and patients for transplant in place, Improvement in screening of ward admissions & PD patients needed. |   |                       |
| Actions taken   | Results presented at a Monday Meeting & discussed at the ward meeting     |                       |
|   |   |                       |
| Action Items  | Person Responsible  | Deadline              |
| Update Renal Unit MRSA Screening guidelines for DMS   | CI  | 30/4/11               |
| 1 Month prospective audit   | CI  | 30/6/11               |
| Dialysis Access Audit   |   |                       |
| Supervisor  | Carol Inward  |                       |
| Standards   | Renal Association Standards   |                       |
| Results: Documentation of preparation for dialysis needs improvement.   |   |                       |
|   |   |                       |
| Actions Taken   | Dialysis care pathway working group established                           |                       |
|   |   |                       |

| Action Items                       | Person Responsible                            | Deadline              |
|------------------------------------|---|-----------------------|
| Care pathway to be implemented     | AJ & SD                                       | 30/9/11               |
| Re-audit                           | AJ & SD                                       | 30/6/12               |
| <b>Audit Project Status Report</b> |   |                       |
| 3.12.2011                          | Carol Inward & Dan Speakman                   | Paediatric Nephrology |
| <b>Renal Transplantation</b>       |   |                       |
| Supervisor                         | Dr Jan Dudley                                 |                       |
| Standards                          | BTS & local guidelines                        |                       |
| Results: Good transplant outcome.  |   |                       |
|                                    |   |                       |
| Actions Taken                      | Results presented to multi-professional team. |                       |
| Action Items                       | Person Responsible                            | Deadline              |
| Review transplant protocol         | JD  | 1/6/11                |
| Re-audit                           | JD  | 1/9/13                |

| <b>ERF Audit</b>   |  |                       |
|--|--|-----------------------|
| Supervisor   | Dr Jane Tizard                                 |                       |
| Standards  | BAPN/BAPN standards                            |                       |
| Results: Improvements in management of anaemia and bone biochemistry needed                        |  |                       |
|  |  |                       |
| Actions taken  | Results presented to MDT.                      |                       |
| Monthly dialysis meeting established to review achievement of audit standards & recommend actions. |  |                       |
| Action Items   | Person Responsible                             | Deadline              |
| Participate in national audits of management of anaemia & infant dialysis                          | CI & EJT                                       | 1/7/11                |
| Review Paediatric Registry Report  | C1   | 30/5/11               |
| <b>Antibiotic Prescribing</b>  |  |                       |
|  |  |                       |
| Standards  | Trust Infection Control Policy                 |                       |
| Results: Compliance with standards improving   |  |                       |
| Actions Taken  | Review drug charts daily.                      |                       |
| Action Items   | Person Responsible                             | Deadline              |
| Remind trainees of antibiotic prescribing policy   | JD   | 10/3/11               |
| <b>Audit Project Status Report</b>   |  |                       |
| March 2011   | Carol Inward & Dan Speakman                    | Paediatric Nephrology |
| <b>CQC Nutrition Standards</b>   |  |                       |
| Supervisor   | Sarah Trace                                    |                       |
| Standards  | Care Quality Commission Core Standards.        |                       |
| Results: Good compliance with nutritional assessment and food provision                            |  |                       |
| Uninterrupted mealtime needs improvement.  |  |                       |
| Actions taken  | Results discussed with multi-professional team |                       |
| Action Items   | Person Responsible                             | Deadline              |
| Avoid ward rounds between 12 00 & 12 30  | Consultant Staff                               | 1/3/11                |
| <b>Hand Hygiene Audit</b>  |  |                       |
| Supervisor   | Dan Speakman                                   |                       |
| Standards  | Trust Infection Control Policy                 |                       |
| Results: Good compliance   |  |                       |
| Actions  | Continue                                       |                       |

| Action Items                              | Person Responsible                           | Deadline |
|---|--|----------|
| None required                             |  |          |
| <b>C Diff Audit</b>                       |  |          |
| Supervisor                                | Dan Speakman/Rachel Hughes                   |          |
| Results                                   | Good compliance, data submitted via intranet |          |
| Standards: Trust Infection Control Policy |  |          |
| Actions Taken                             | continue                                     |          |
| Action Items                              | Person Responsible                           | Deadline |
| Non required                              |  |          |

| Audit Project Status Report               |                             |                       |
|---|-----------------------------|-----------------------|
| 3.12.2011                                 | Carol Inward & Dan Speakman | Paediatric Nephrology |
| Audit Topic Selection 2011-2012           |                             |                       |
| Proposed topics                           | Renal biopsy                |                       |
|   |                             |                       |
|   |                             |                       |
| Action Items                              | Person Responsible          | Deadline              |
| <b>15 minute Hand Hygiene Audit</b>       |                             |                       |
| Supervisor                                | Dan Speakman                |                       |
| Results                                   | Good compliance             |                       |
| Standards: Trust Infection Control Policy |                             |                       |
| Actions                                   | Continue                    |                       |
| Action Items                              | Person Responsible          | Deadline              |
| Non required                              |                             |                       |
| Saving Lives Audit                        |                             |                       |
| Supervisor                                | Dan Speakman                |                       |
| Results                                   | Good Compliance             |                       |
| Standards: Trust Infection Control policy |                             |                       |
| Actions                                   | Continue data collection    |                       |
| Action Items                              | Person Responsible          | Deadline              |
| Non required                              |                             |                       |
|   |                             |                       |

| HRG Data  |   |          |
|---|---|----------|
|   |   |          |
| Audit Topic Selection 2011-2012   |   |          |
| supervisor  | Caroline Haynes/Dan Speakman  |          |
| Results   | Audit forms completed by nursing staff on the ward and submitted to Caroline Haynes |          |
| Standards: analyses dependency of children nursed on wards, Trust led project |   |          |
|   |   |          |
| Action Items  | Person Responsible  | Deadline |
| continue  |   |          |
|   |   |          |
| PPE Audit   |   |          |
| Supervisor  | Rachel Hughes/Dan Speakman  |          |
| Results   | Audit data submitted online, good compliance  |          |

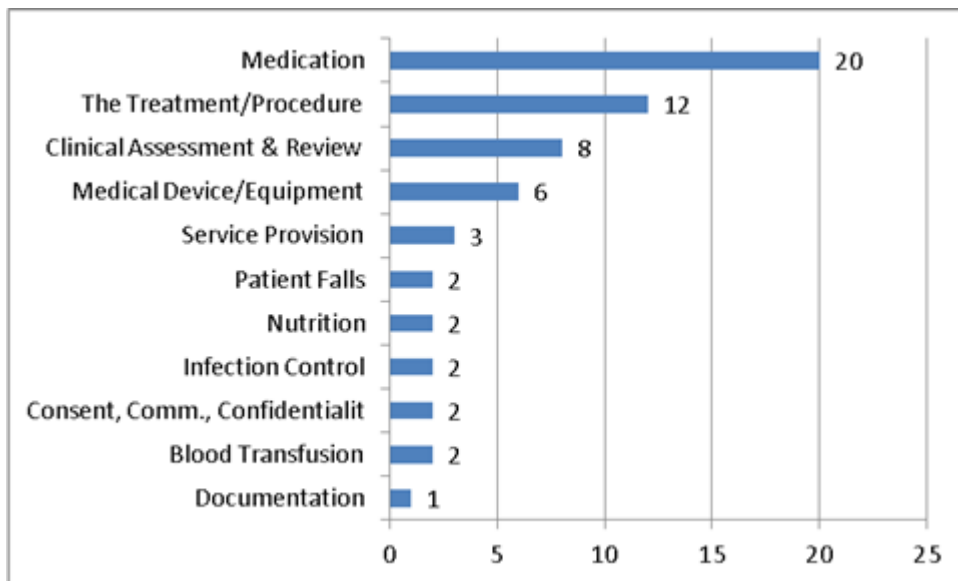
| Standards: Trust Infection Control Policy |                    |          |
|---|--------------------|----------|
| Action Items                              | Person Responsible | Deadline |
| continue                                  |                    |          |
|   |                    |          |

## Patient safety

01/04/2010 – 31/03/2011

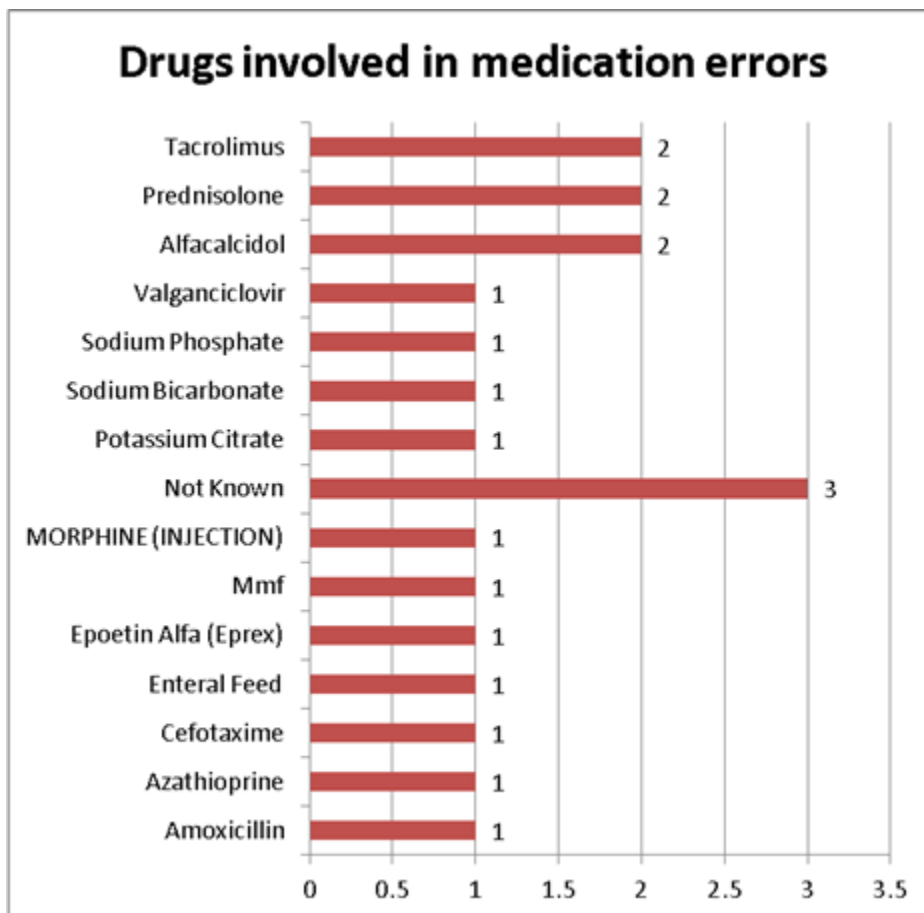
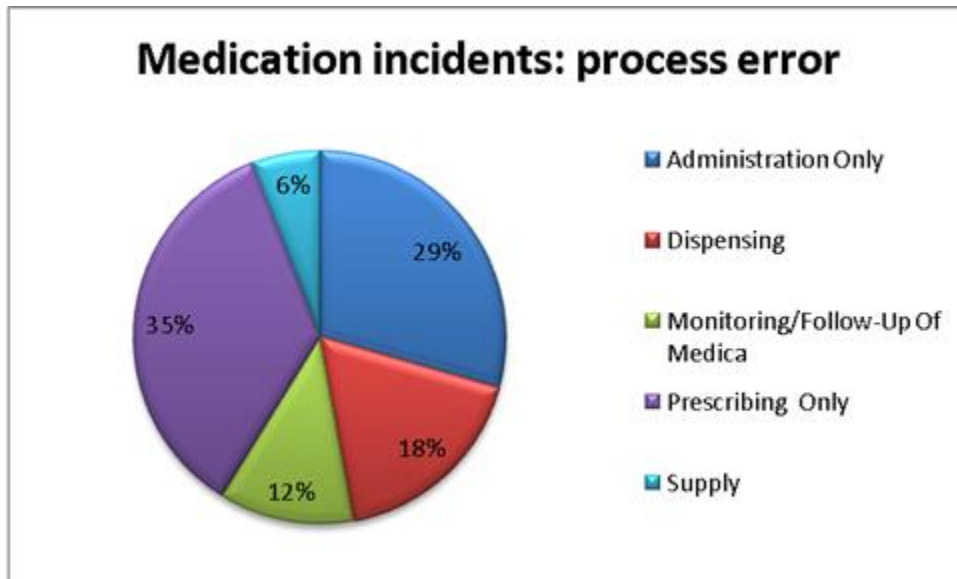
- 60 patient safety incidents reported over the financial year

### Causes for Ward 37 incidents

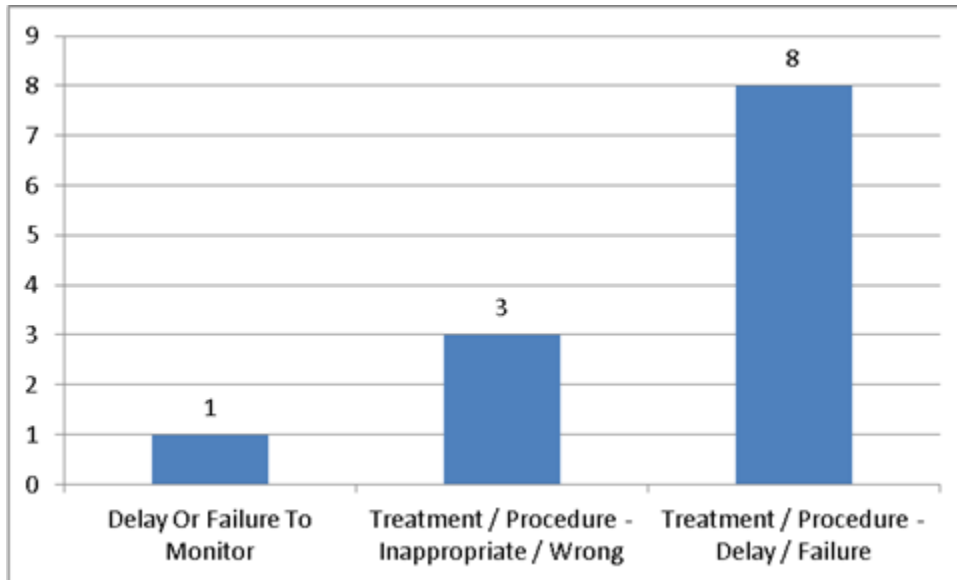


Analysis of incidents reported

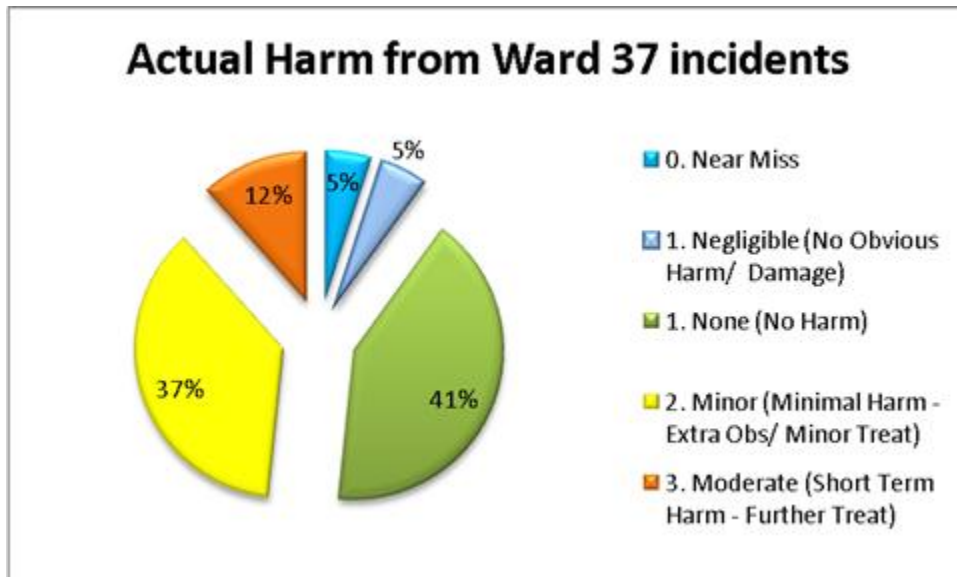
The top cause for ward 37 is ‘Medication errors’ which is a broad term – included below are the process errors that led to the incident.



The second highest reported incident was ‘The treatment and procedure’



Actual harm from Ward 37 incidents



There were 7 ‘moderate’ harm incidents reported – for Moderate harm to occur the patient, this could incur up to 15 days additional stay in hospital (according to the NPSA Patient Safety Consequences Matrix) which is the equivalent to 105 extra days\* to the Trust.

|  |
|--|
| <b>3</b>   |
| <b>Moderate</b>  |
| Moderate injury requiring professional intervention<br>Requiring time off work for 4-14 days<br>Increase in length of hospital stay by 4-15 days<br>RIDDOR/agency reportable event<br>An event which impacts on a small number of patients |

\*(based on 7 moderate incidents x 15 additional days stay).  
 This is used as an extreme example and this could be challenged by correct grading of the incident.

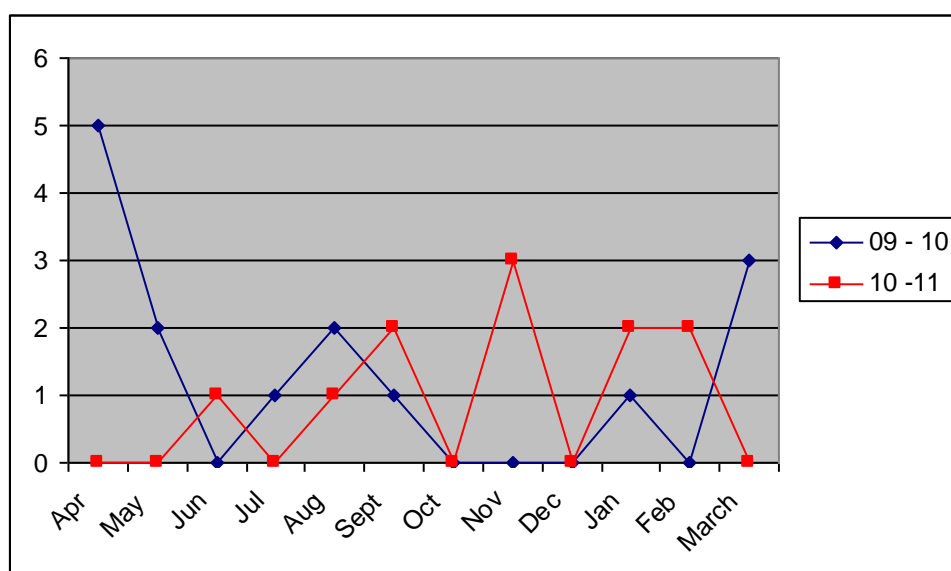
The incidents rated “Moderate” have all been addressed at Specialty, Divisional or Trust level as appropriate. The actions taken include a hospital wide audit of the use of the paediatric early warning tool, an extension of the hours of the paediatric outreach service and a review of the arrangements for providing emergency anaesthetic support for cardiopulmonary resuscitation in the children’s hospital out of hours. No long-term harm to the patient resulted from any of the reported incidents.

Enquiries received via LIAISE and the Patient Support Team  
1<sup>st</sup> April 2010 to 31<sup>st</sup> March 2011  
Ward 37

Data regarding patient enquiries is recorded on the Ulysses data collection system which includes formal enquiries and informal enquiries

**Contacts**

Excluding outliers, no formal complaints and 11 informal enquiries were recorded during the period. These divide across the period as shown below:

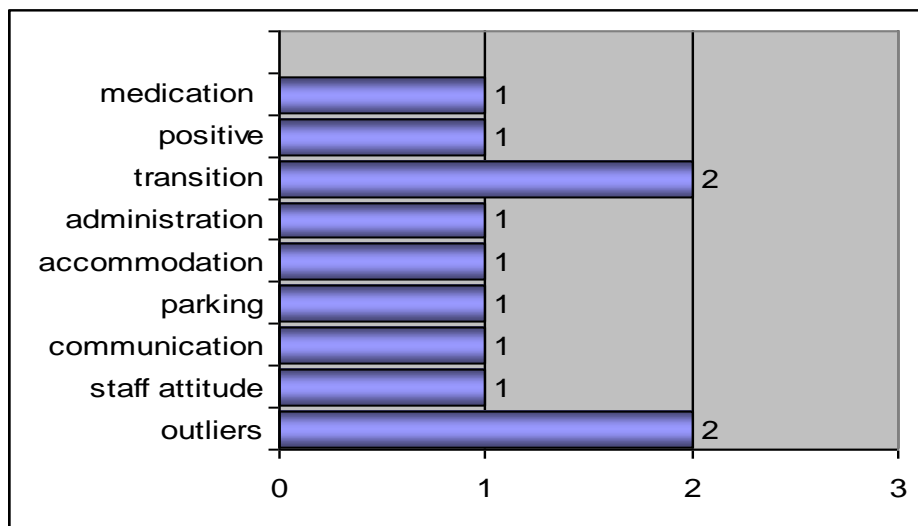


In comparison to 2009-10, enquiry levels seem similar, although without the peaks previously shown in March and April.

Peaks in informal enquiries across all services often occur during school holidays, with the exception of Christmas, which usually sees a decrease in enquiry levels, followed by a comparative increase in January. This may relate changes in ward staffing due to term time working or changes to the complexity of family arrangements during these times. The pattern for Ward 37 enquiries during this period is not dissimilar to this general trend but as once again we are looking at a small number of responses, it is difficult to draw any robust conclusions in relation to season variations.

#### Themes

From this year's data, the following themes were identified:



The most common enquiry received via LIAISE is from patients travelling from outside of the Bristol area, looking for accommodation. The second relates to emotional and practical support around being away from home, which includes signposting to social work or benefits advice, hospital and visiting guidelines or local information. For this year, the majority of such enquiries have not included the ward number as the information required by the client does not change based on the ward. However, one accommodation enquiry was specific enough to be recorded against the ward, as was a request for support in lodging a parking appeal.

Transition enquiries relate to requests for support for patients who have moved into adult services, one relating to social and emotional support and the other to targeted information for patients with learning difficulties.

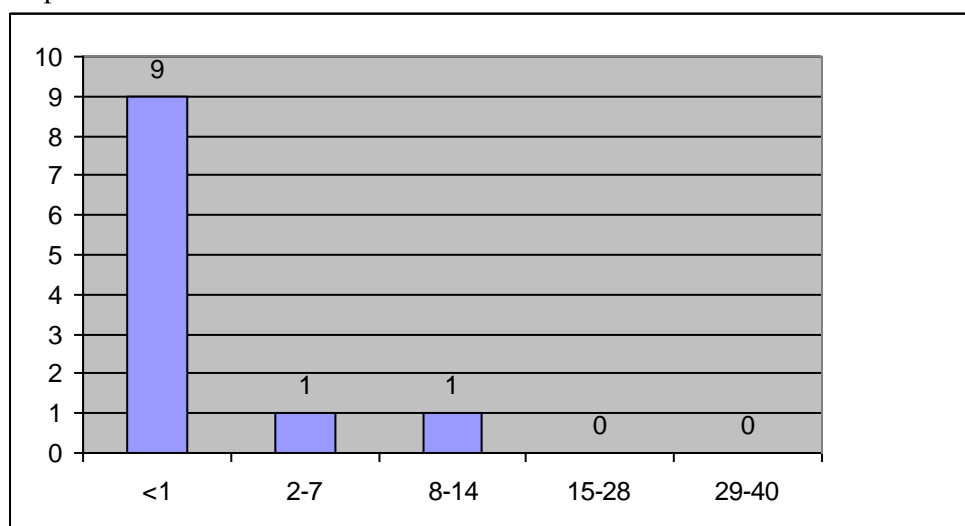
The medication enquiry related to a dose of Heparin which had been incorrectly given due to variants in the tube markers. This was also reported as an incident and a protocol for double checking was put in place together with clarification of the interpretation of tube markers both to the staff member concerned and the wider team. The incident resulted in no harm to the patient.

The staff attitude enquiry related to a renal patient but concerned a staff member they encountered elsewhere in the hospital, rather than a member of the renal team. The communication issue did relate to the renal clinical team where a family had understood that

they were to meet with a member of the team at a specific time. This time subsequently could not be honoured but the change was not communicated to the family. This is a familiar theme across all specialities, due to constantly changing priorities for staff, but if not effectively managed can have a significant impact on the anxiety levels and therefore capacity to co-operate demonstrated by families.

The positive enquiry related to a request for information on making a donation from a family who had been treated by the team and wished to show their appreciation.

#### Response times



All enquiries received a response within 24 hours, with the exception of the enquiry relating to a medication error which took 2 days to resolve and the enquiry regarding communication, which was closed after 10 working days as the enquirer did not respond to requests for further information.

#### Clinical Risks

Risk assessment of the water purification system was carried out in 2008 and has been reviewed regularly by the Divisional Board since then. The assessment is summarised here:

##### Situation

High bacterial counts in the water purification system used for renal dialysis which do not always return to zero after monthly cleaning

##### Background

The water treatment plant was installed in BRHC before the renal unit was planned to transfer and the system therefore awkwardly configured and 8 years old.

It is suspected that rarely used PICU ports (5 in total) contribute to this.

The ports are now flushed weekly and the system cleaned twice a month.

##### Assessment

High Risk

##### Recommendations:

Consider whether to

1. Remove 3 ports from PICU. The advantage being a probable reduction in the bacterial counts in the water. Disadvantage – inability to cope with more than 2 haemodialysis patients in PICU (potential problems managing an E Coli epidemic or a requirement to close renal ward)

or

## 2. Accept current controls and place on risk register

The actions taken this year have been to place this issue on the Trust risk register and to close the ports on PICU. A request for funding of a new system has been accepted by the Decontamination Committee.

### 8.12 EDUCATION AND TRAINING

The Unit continues with an excellent reputation for training and is recognised by the Royal College of Paediatrics and Child Health (RCPCH) for subspecialty training in paediatric nephrology. Dr Hugh McCarthy was the Grid trainee from September 2007 to September 2009. He is now working for an PhD developing the Rare diseases registry (RaDaR). Dr Nick West replaced Dr McCarthy in the Specialty training post from September 2009-March 2011. From September 2010 Dr Ramnath Balasubramanain joined the team on the IPTS(International Paediatric Training Scheme) for a year.

We have seamlessly accommodated the changes of Modernising Medical Careers and are providing training and assessment for Foundation trainees and Specialty registrars at all levels of training. We continue with our broad postgraduate educational programme, which covers basic science, evidence based reviews, state of the art talks together with audit and research presentations.

### 8.13 RESEARCH

#### LABORATORY RESEARCH - GLOMERULAR CELL BIOLOGY

Moin Saleem, Professor of Paediatric Renal Medicine

Richard Coward MRC Senior Lecturer in Paediatric Nephrology

Lindsay Keir, Hugh McCarthy, Hannah Rhodes – Clinical Training Fellows

The glomerulus is the elemental unit of kidney filtration, and the glomerular podocyte is a central component of this filtration barrier, disruption of which is the key feature of a multitude of kidney diseases.

One of the main focuses of the Academic Renal Unit is the study of podocyte biology, with a team of clinical paediatric and adult nephrologists at various levels of training, working side by side with basic scientists.

The resources we use are unique in the world, comprising human conditionally immortalised podocyte cell lines from normal kidneys and from patients with congenital mutations in key podocyte genes, as well as the more recent development of human conditionally immortalised endothelial cell lines, the other key cell of the filtration barrier.

Current laboratory projects fall into six basic areas:

1. The role of plasma factors in the pathogenesis of nephrotic syndromes. This utilises the resource of patients' plasma and its effect on the cell lines, concentrating on the slit diaphragm proteins, actin cytoskeleton and the signalling pathways that connect them.
2. The role of the podocyte in diabetic nephropathy. This arena of work builds on our observation that the podocyte is a novel insulin sensitive cell, and addresses the

biological basis of this clinical renal disease which is by far the biggest cause of end-stage renal failure worldwide, and whose incidence is rapidly rising.

This work is being led by Dr Coward, using sophisticated in vivo models and techniques learnt in Toronto, which are now being transferred to Bristol.

We have just published a landmark paper in Cell Metabolism, the first from this new line of work, detailing the role of insulin in maintenance of normal glomerular filtration.

3. Influences on podocyte differentiation – we are investigating the roles of genes, cytokines, endothelial cells, matrix etc. as components of the podocyte environment that influence mature differentiation. This includes work that has revealed that mature podocytes display key features of smooth muscle cells, and will address how the podocyte changes its developmental profile in disease.
4. The role of the podocyte in the pathogenesis of haemolytic uraemic syndrome (HUS)
5. Co-culture of glomerular endothelial cells and podocytes, to engineer the properties of the intact filtration barrier, in order to study its specialised functions in vitro.
6. The molecular biology of paediatric renal stone disease.

Secondly, we have taken the lead role in the development of a National Registry for Renal Rare Disease (RaDaR). This is a MRC funded project to develop a national web based infrastructure for comprehensive collection, phenotyping and management of rare renal diseases. All UK units are participating, with the plan to add new disease groups on an ongoing basis. This will be a major new resource for the management of renal rare disease, both in children and adults.

The Academic Renal Unit (ARU), based in a brand new research building in Southmead Hospital, is a thriving research environment with currently 22 research staff.

This is a mix of laboratory technicians, clinical and non-clinical PhD students, MD students post-doctoral researchers and a senior non-clinical Lecturer, Dr Gavin Welsh.

Senior clinical staff consist of adult and paediatric nephrologists, and Professor Saleem has taken over from Professor Peter Mathieson as Head of the ARU.

Current PhD students

- 1) Hugh McCarthy – Clinical Training Fellow 2009-2012
- 2) Lindsay Keir – MRC Clinical Training Fellow – 2010 – 2013
- 3) Carl May – KRUK studentship – 2010-2013
- 4) Abigail Ley – KRUK studentship 2011-2014
- 5) Hannah Rhodes – Clinical training fellow (paediatric surgery)

Collaborations.

Our main collaborators are:

1. Susan Quaggin, Samuel Lunenfeld Institute, Toronto. Dr Quaggin has developed the world's leading laboratory in studying glomerular disease using in vivo models. Dr Coward has completed 20 months in Toronto learning techniques and developing important new models. Dr Keir is currently in this laboratory as part of her MRC Training Fellowship

2. Ania Koziell, Molecular Medicine Unit, Evelina Children's Hospital, London

3. Professors David Bates and Steve Harper – Microvascular Research Labs, University of Bristol. We have many links with this group, particularly in the biology of Vascular Endothelial Growth Factor (VEGF).

We have a number of other collaborators worldwide, particularly with respect to utilising our cell line for specific projects, and have initiated active collaborations with at least 50 of these so far, with our cell lines being distributed to over 100 laboratories worldwide.

#### Industrial Collaborations

We have signed contracts with Evotec (Hamburg) and Glaxo SmithKline for collaborative work on glomerular disease and compound identification projects

We currently have 4 other active collaborative agreements with pharmaceutical companies signed.

#### RESEARCH GRANTS OBTAINED

2011 KRUK/BKPA Rare Disease Registry – infrastructure grant – 3 yrs - £500,000

2011 Kidney Research UK – PhD studentship - £60,000 - The role of Nephrin in Diabetic Nephropathy

2010 Medical Research Council – Research Training Fellowship – 3yrs - £200,000

The pathogenesis of haemolytic uraemic syndrome: the role of the podocyte

2010- Diabetes UK Glomerular endothelial glycocalyx and its dysregulation in diabetes - £160,000

2010 KRUK – The role of insulin like growth factors in podocyte and glomerular function – 2 years - £136,000

2010 Kidney Research UK – PhD studentship - £58,000 CD2AP – a novel regulator of podocyte differentiation

2010 Kids Kidney Research – Contribution to PhD studentship – Development of a Renal Rare Disease Registry - £68000

In addition the laboratory gets major support from the Nephrotic Syndrome Trust ([www.nstrust.co.uk](http://www.nstrust.co.uk)). In 2010 alone NeST raised over £50,000 for research into nephrotic syndrome.

#### CLINICAL RESEARCH

National Study of Rare Diseases in Renal Medicine

(RaDaR)

A major initiative to set up and run a national infrastructure for renal rare disease cohort data collection and follow up, run in partnership with the UK Renal Registry, BAPN and Renal Association.

Funding is from the Medical Research Council, Kidney Research UK, BKPA and North Bristol NHS Trust.

Multicentre trials

In addition to these local studies the department participates in a number of multi-centre projects including:

- PREDNOS, Nephrotic syndrome-long or short course of steroids at initial presentation
- Takeda antihypertensive Phase I study
- Cinacalcet study
- Long term follow up of children with SLE via JSLE registry

#### 8.14 Presentations

1. Claire Rigotherier , Moin A Saleem , Christian Combe, and Gavin I Welsh.  
Modification of the cellular characteristics of IQGAP1 after exposure to NS plasma and puromycin : a stage of foot process effacement during NS ? French Society of Nephrology 2010
2. Ramadan Sarrab, Rachel Lennon, Lan Ni, Gavin Welsh, Moin Saleem. Establishment of conditionally immortalised human glomerular mesangial cells in culture. Renal Association 2010

3. Mervi E. Hyvönen, Pauliina Saurus, Anita Wasik, Eija Heikkilä, Moin Saleem, Harry Holthöfer and Sanna Lehtonen Lipid phosphatase SHIP2 downregulates insulin signalling in cultured podocytes and is upregulated in glomeruli of diabetic animal models. International Podocyte Congress 2010
4. Fiona Wu, Moin A Saleem, Nicole B. Kampik, Timothy J. Satchwell, Rosalind C. Williamson, Simone M. Blattner, Lan Ni, Tibor Toth, Graham White, Seth L. Alper, Carsten A. Wagner and Ashley M. Toye A novel role of kidney anion exchanger-1 (kAE1) – interaction with nephrin in podocytes. International Podocyte Congress 2010
5. Simran Khurana, Sharmistha Chakraborty, Minh Lam, Leslie A. Bruggeman, Moin A. Saleem, Peter W. Mathieson, and Hung-Ying Kao. Regulation of podocyte gene expression by alpha actinin 4 (ACTN4) and nuclear hormone receptors. International Podocyte Congress 2010
6. Rachel Lennon, Jonathan D Humphries, Mike Jackson, Simon C Satchell, Peter W Mathieson, Moin A Saleem, Paul E Brenchley, Martin J Humphries. Proteomic analysis of cell adhesion in human glomerular podocytes and endothelial cells International Podocyte Congress 2010
7. Hugh McCarthy. David Ansell, Fiona Braddon, Mark Taylor, Moin Saleem. RenalRaDaR.org – The Inception of The UK Registry of Rare Renal Disease to Enable Research Studies on a National Scale IPNA 2010
8. Moin Saleem New Advances in Podocyte Biology.–Entente Cordiale Meeting, Paris 2011
9. Moin Saleem. Understanding nephrotic syndromes through advances in podocyte biology. Korean Society of Nephrology 2011.
10. Moin Saleem. What is a podocyte? Current concepts in health and disease. Korean Society of Nephrology 2011.
11. Moin Saleem. Advances in Podocyte Biology Renal Association 2011.
12. Keir LS, Coward RJM, Spooner R, Richards A, Welsh GI, Saleem MA The podocyte is the initial target in the renal pathogenesis of diarrhoea-associated haemolytic uraemic syndrome. Academic Paediatrics Association 2011 – WINNER best abstract prize
13. GI Welsh, LJ Hale, V Eremina, M Jeansson, M. Bek, Y Maezawa, R Lennon, DA Pons, RJ Owen, SC Satchell, MJ Miles, CJ Caunt, CA McArdle, T Toth, AM Herzenberg, H Pavenstädt, J M Tavaré, CR Kahn, PW Mathieson, SE Quaggin, MA Saleem and RJM Coward Specific loss of insulin signalling to the kidney podocyte recapitulates features of diabetic nephropathy. Renal Association Manchester 2010
14. LJ Hale, GI Welsh, C Perks, A Murphy, MA Saleem, PW Mathieson, J Holly, N Hardouin, RJ Coward. Autocrine regulation of the Insulin like growth factors are critical for podocyte survival and glomerular function of the kidney. “Specific loss of

insulin signalling to the kidney podocyte recapitulates features of diabetic nephropathy Renal Association Manchester 2010

15. GI Welsh, LJ Hale, V Eremina, M Jeansson, M. Bek, Y Maezaw, R Lennon, DA Pons, RJ Owen, SC Satchell, MJ Miles, CJ Caunt, CA McArdle, AM Herzenberg, H Pavenstädt, J M Tavaré, CR Kahn, PW Mathieson, SE Quaggin, MA Saleem and RJM Coward. Specific loss of insulin signaling to the kidney podocyte recapitulates features of diabetic nephropathy Keystone meeting Whistler Vancouver 2010
16. Coward RJ. Inherited renal tubulopathies -British association for clinical biochemistry invited talk Bristol 2010
17. Coward RJ Developing a medical academic career Invited speaker for Academy of Medical Sciences Bristol 2010
18. MA Saleem RADAR - An Interactive Resource for learning from Paediatric and Adult Rare Diseases Renal Association – Manchester 2010
19. MA Saleem The podocyte slit diaphragm – adaptation to achieve a unique function Physiological Society, annual meeting, Manchester 2010
20. Sarreb Ramadan, Ania Koziell, Lan Ni, Gavin Welsh, Moin Saleem CD2AP is a key molecule to maintain the epithelial phenotype of the podocyte Renal Association 2010
21. Hugh McCarthy BSc MD, David Ansell MD, Fiona Braddon, Mark Taylor MD, Moin Saleem MD PhD RenalRaDaR.org – The Inception of The UK Registry of Rare Renal Disease to Enable Research Studies on a National Scale Renal Association 2010
22. Kim J, Goodship T, Tizard J, Inward C. Early intensive plasma exchange (PEX) for atypical haemolytic uraemic syndrome (aHUS) may slow progression to end-stage renal failure (ESRF) IPNA 2010
23. Krischock LA, van Stralen K, Jager K, Verrina E, Groothoff JW, Schaefer F, Tizard J The prevalence and predictors of anaemia in European Children with established renal failure. IPNA 2010
24. van Stralen K, Tizard J, Jager K, Groothoff JW, Schaefer F, Verrina E Determinants of eGFR at start of renal replacement therapy in children IPNA 2010
25. Amelia Holme, Carol Inward, Richard Coward ARC Syndrome: Rare, Fatal and Easily Recognised? South West Paediatric Club November 2010 (won the poster prize)
26. Children Y. Tse, L. Kerecuk, C. Inward, R. Sinha, J. Shield, M. Sinha .Longitudinal Change in Body Mass Index (BMI) Following Renal Transplantation in UK on behalf of the, British Association of Paediatric Nephrology, United Kingdom IPNA September 2010
27. Maintaining an Adequate Intra-Operative and Immediate Post-Operative Systolic Blood Pressure during Renal Transplantation in Children under Five Influences

Outcome. McCarthy\_H, Dudley J. International Pediatric Nephrology Association Congress. September 2010

28. Isolated Echogenic Kidneys from a Single Tertiary Centre over a 10 Year Period. Edwards S, West N, Dudley J, Overton T. International Pediatric Nephrology Association Congress. September 2010

#### 8.15 Publications

1. Wang B, Herman-Edelstein M, Koh P, Burns W, Jandeleit-Dahm K, Watson A, Saleem M, Goodall GJ, Twigg SM, Cooper ME, Kantharidis P. Catherin expression is regulated by miR-192/215 by a mechanism that is independent of the profibrotic effects of transforming growth factor-beta. *Diabetes*. 2010 Jul;59(7):1794-802.
2. Worthmann K, Peters I, Kümpers P, Saleem M, Becker JU, Agustian PA, Achenbach J, Haller H, Schiffer M. Urinary excretion of IGFBP-1 and -3 correlates with disease activity and differentiates focal segmental glomerulosclerosis and minimal change disease. *Growth Factors*. 2010 Apr;28(2):129-38.
3. Oshima Y, Kinouchi K, Ichihara A, Sakoda M, Kurauchi-Mito A, Bokuda K, Narita T, Kurosawa H, Sun-Wada GH, Wada Y, Yamada T, Takemoto M, Saleem MA, Quaggin SE, Itoh H. Prorenin Receptor Is Essential for Normal Podocyte Structure and Function. *J Am Soc Nephrol*. 2011 Nov 3.
4. Ristola M, Arpiainen S, Saleem MA, Holthöfer H, Lehtonen S. Transcription of nephrin-Neph3 gene pair is synergistically activated by WT1 and NF- $\kappa$ B and silenced by DNA methylation. *Nephrol Dial Transplant*. 2011 Oct 6. [Epub ahead of print] PMID: 21980157
5. Prabakaran T, Nielsen R, Larsen JV, Sørensen SS, Feldt-Rasmussen U, Saleem MA, Petersen CM, Verroust PJ, Christensen EI. Receptor-mediated endocytosis of  $\alpha$ -galactosidase A in human podocytes in Fabry disease. *PLoS One*. 2011;6(9):e25065. Epub 2011 Sep 19.
6. Sanchez-Niño MD, Sanz AB, Sanchez-Lopez E, Ruiz-Ortega M, Benito-Martin A, Saleem MA, Mathieson PW, Mezzano S, Egido J, Ortiz A. HSP27/HSPB1 as an adaptive podocyte antiapoptotic protein activated by high glucose and angiotensin II. *Lab Invest*. 2011 Sep 19. doi: 10.1038/labinvest.2011.138. [Epub ahead of print]
7. Eyre J, Burton JO, Saleem MA, Mathieson PW, Topham PS, Brunskill NJ. Monocyte- and Endothelial-Derived Microparticles Induce an Inflammatory Phenotype in Human Podocytes. *Nephron Exp Nephrol*. 2011 Aug 18;119(3):e58-e66. [Epub ahead of print]
8. Slater SC, Beachley V, Hayes T, Zhang D, Welsh GI, Saleem MA, Mathieson PW, Wen X, Su B, Satchell SC. An in vitro model of the glomerular capillary wall using electrospun collagen nanofibres in a bioartificial composite basement membrane. *PLoS One*. 2011;6(6):e20802. Epub 2011 Jun 24.

9. Sarrab RM, Lennon R, Ni L, Wherlock MD, Welsh GI, Saleem MA. Establishment of conditionally immortalized human glomerular mesangial cells in culture, with unique migratory properties. *Am J Physiol Renal Physiol*. 2011 Nov;301(5):F1131-8.
10. Shimada M, Ishimoto T, Lee PY, Lanaspá MA, Rivard CJ, Roncal-Jimenez CA, Wymer DT, Yamabe H, Mathieson PW, Saleem MA, Garin EH, Johnson RJ. Toll-like receptor 3 ligands induce CD80 expression in human podocytes via an NF- $\kappa$ B-dependent pathway. *Nephrol Dial Transplant*. 2011 May 26. [Epub ahead of print]
11. Zhao S, Gu Y, Coates G, Groome LJ, Saleem MA, Mathieson PW, Wang Y. Altered nephrin and podoplanin distribution is associated with disturbed polarity protein PARD-3 and PARD-6 expressions in podocytes from preeclampsia. *Reprod Sci*. 2011 Aug;18(8):772-80.
12. Qu H, Tu Y, Shi X, Larjava H, Saleem MA, Shattil SJ, Fukuda K, Qin J, Kretzler M, Wu C. Kindlin-2 regulates podocyte adhesion and fibronectin matrix deposition through interactions with phosphoinositides and integrins. *J Cell Sci*. 2011 Mar 15;124(Pt 6):879-91.
13. Pawluczyk IZ, Yang B, Patel SR, Saleem MA, Topham PS. Low-level C-reactive protein levels exert cytoprotective actions on human podocytes. *Nephrol Dial Transplant*. 2011 Aug;26(8):2465-75.
14. George B, Vollenbröker B, Saleem MA, Huber TB, Pavenstädt H, Weide T. GSK3 $\beta$  inactivation in podocytes results in decreased phosphorylation of p70S6K accompanied by cytoskeletal rearrangements and inhibited motility. *Am J Physiol Renal Physiol*. 2011 May;300(5):F1152-62.
15. Welsh GI, Hale LJ, Eremina V, Jeansson M, Maezawa Y, Lennon R, Pons DA, Owen RJ, Satchell SC, Miles MJ, Caunt CJ, McArdle CA, Pavenstädt H, Tavaré JM, Herzenberg AM, Kahn CR, Mathieson PW, Quaggin SE, Saleem MA, Coward RJ. Insulin signaling to the glomerular podocyte is critical for normal kidney function. *Cell Metab*. 2010 Oct 6;12(4):329-40.
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- mediates internalization of HIV-1 into human podocytes. *Am J Physiol Renal Physiol.* 2010 Sep;299(3):F664-73.
20. Edwards AG, McCarthy H, Morgan JD, Saleem MA. Paediatric non-heart-beating renal transplantation. *Arch Dis Child.* 2010 Oct;95(10):843-4.
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  23. Sanchez-Niño MD, Sanz AB, Carrasco S, Saleem MA, Mathieson PW, Valdivielso JM, Ruiz-Ortega M, Egido J, Ortiz A. Globotriaosylsphingosine actions on human glomerular podocytes: implications for Fabry nephropathy. *Nephrol Dial Transplant.* 2011 Jun;26(6):1797-802.
  24. Dai C, Saleem MA, Holzman LB, Mathieson P, Liu Y. Hepatocyte growth factor signaling ameliorates podocyte injury and proteinuria. *Kidney Int.* 2010 Jun;77(11):962-73.
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#### Reviews

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Book chapters

1. Brogan PA, Tizard EJ; Wegener's Granulomatosis, Polyarteritis Nodosa, Bechet's and Relapsing Polychondritis in: Textbook of Paediatric Dermatology. 3rd edition Edit Harper J, Oranje A, Prose N; Chapter 26.10

## **CHARITY**

**The charity NeST (Nephrotic Syndrome Trust), launched at Twickenham Rugby Ground in June 2005 by the New Zealand rugby legend Jonah Lomu, who is our ambassador. The charity is also sponsored by Brita Water Filters. The proceeds all go towards the ongoing research in Bristol, and details can be found on [http://www.brita.net/uk/brita\\_charity.html](http://www.brita.net/uk/brita_charity.html)**

## **9 DEVELOPMENT PLANS AND QUALITY INITIATIVES**

- **Maintain high quality service during ward re-development which is part of the BRHC plan to amalgamate specialist children's services.**
- **Introduction of electronic discharge system**
- **Develop ABO incompatible transplantation**
- **Develop simulation exercises for training in haemodialysis in infants**
- **Enhancement of Transition services through involvement with Supporting Young Adults Project**
- **Enhancement of care plans through successful bid for funding from NHS Kidney Care**
- **Enhancement of networked dietetic service**
- **Change management of atypical HUS through use of Eculizumab (may depend on National Commissioning)**
- **Review of Outpatient services**