The Renal Association
UK Renal Registry
Southmead Hospital
Southmead Road
Bristol, BS10 5NB, UK

Telephone
+44 (0) 117 323 5665

Fax
+44 (0) 117 323 5664

Email
renalregistry@renalregistry.nhs.uk

Web site
www.renalreg.org

Director
Ron Cullen

Medical Advisor
Terry Feest

Management Team
David Bull
Hilary Doxford
Retha Steenkamp

Project Management
Sue Shaw

Clinical Informatics
Fiona Braddon
Shaun Mannings

Clinical Data Management
Fran Benoy-Deeney
Lynsey Billett
Paul Dawson
Jo Wilson
Sarah Wood

Programmers
Matthew Brealey
George Swinnerton

Business Support
Steph Shearn
Laura Woodward
Foreword

Welcome to the Renal Registry report for 2012. Although the renal community has become used to the annual publication of this document, we should not take it for granted. The huge effort that goes into production of the report places nephrology ahead of most other specialties in terms of national audit. We should be proud of what our registry has achieved in its short history. A recent article in the BMJ, which discussed publication of information on the performance of doctors and institutions since the Bristol inquiry into paediatric cardiac surgery, praised our efforts [1]. Benchmarking against the achievements of the cardiothoracic surgeons, the author notes “so far, other specialities have been reluctant to follow suit” but goes on to state that “Nephrology is the notable exception”, describing how we publish our outcomes on adequacy of dialysis, haemoglobin and blood pressure to allow “clinical staff, commissioners and patients to… see how their renal centre is performing [against] specific national targets”. This culture of transparency is likely to be driven forward by public and patient pressure to improve quality of care in the light of the Francis enquiry.

In our speciality, we teach our patients to be interested in their “numbers” and to track these on Renal Patient View, but blood test results are often somewhat peripheral to the patient experience. The drive to collect patient reported outcome/experience measures (PROMs and PREMs) follows publication of a report entitled “High Quality Care for All – NHS Next Stage Review” by Lord Darzi. As usual, the Registry is ahead of the game and will shortly be conducting a pilot study to assess the feasibility and cost of collecting these measures in the dialysis population. Other Registry projects include collection of data in stage 4–5 CKD patients, which will allow us to gain a better picture of what happens to patients with end-stage kidney disease, particularly those who, for whatever reason, do not get offered or decline renal replacement therapy. The establishment of Renal RaDaR, the national registry for rare kidney disease, is progressing well and has already proven to be of value in supporting research projects. As these activities progress, we can look forward to a broader dataset being published in future annual reports. We can also expect more timely reporting. According to current projections, we will also be seeing the 2013 report published before the end of this calendar year.

On behalf of the Renal Association, I would like to thank all those who have contributed towards collecting, processing, analysing and publishing the data contained in this 2012 report. This is, of course, a huge collaborative effort involving all renal units in the UK, but special thanks must go to the team in Bristol. The Registry has certainly come a long way in the last 20 years and we can expect some exciting times ahead.

David Wheeler
President, Renal Association

1 Tavere A, Measure your team’s performance, and publish the results. BMJ 2012;345:e4464
Chapters and appendices

Chapter 1  UK RRT Incidence in 2011: National and Centre-Specific Analyses
Chapter 2  UK RRT Prevalence in 2011: National and Centre-Specific Analyses
Chapter 3  Demographic and Biochemistry Profile of Kidney Transplant Recipients in the UK in 2011: National and Centre-Specific Analyses
Chapter 4  Demography of the UK Paediatric Renal Replacement Therapy Population in 2011
Chapter 5  Survival and Causes of Death of UK Adult Patients on Renal Replacement Therapy in 2011: National and Centre-Specific Analyses
Chapter 6  Haemoglobin, Ferritin and Erythropoietin Amongst UK Adult Dialysis Patients in 2011: National and Centre-Specific Analyses
Chapter 7  Clinical, Haematological and Biochemical Parameters in Patients Receiving Renal Replacement Therapy in Paediatric Centres in the UK in 2011: National and Centre-Specific Analyses
Chapter 8  UK Multisite Peritoneal Dialysis Access Catheter Audit for First PD Catheters 2011
Chapter 9  Centre Variation in Access to Renal Transplantation in the UK (2006–2008)
Appendix A  The UK Renal Registry Statement of Purpose
Appendix B  Definitions and Analysis Criteria
Appendix C  Renal Services Described for Non-physicians
Appendix D  Methodology used for Analyses of PCT/HB Incidence and Prevalence and of Standardised Ratios
Appendix E  Methodology for Estimating Catchment Populations of Renal Centres in England for Dialysis Patients
Appendix F  Additional Data Tables for 2011 Incident and Prevalent Patients
Appendix G  UK Renal Registry Dataset Specification
Appendix H  Coding: Ethnicity, EDTA Primary Renal Diagnoses, EDTA Causes of Death
Appendix I  Acronyms and Abbreviations used in the Report
Appendix J  Laboratory Conversion Factors
Appendix K  Renal Centre Names and Abbreviations used in the Figures and Data Tables
Contents

Chapter 1 UK RRT Incidence in 2011: National and Centre-Specific Analyses 1
Julie Gilg, Anirudh Rao, Damian Fogarty 1

Introduction 2
Definitions 2
UK Renal Registry coverage 2
1. Geographical variation in incidence rates 2
2. Demographics and clinical characteristics of patients starting RRT 3
   Methods 3
   Results 8
3. Late presentation and delayed referral of incident patients 22
   Introduction 22
   Results 22
Survival of incident patients 27
International comparisons 27
Summary 27
Acknowledgements 27

Chapter 2 UK RRT Prevalence in 2011: National and Centre-Specific Analyses 29
Catriona Shaw, Rishi Pruthi, David Pitcher, Damian Fogarty 29

Introduction 30
Methods 30
Results 31
   Prevalent patient numbers and changes in prevalence 31
   Prevalent patients by RRT centre 31
   Changes in prevalence 33
   Prevalence of RRT in Primary Care Trusts (PCT) in England, Health and Social Care Areas in Northern Ireland (HB), Local Health Boards in Wales (HB) and Health Boards in Scotland (HB) 36
   Factors associated with variation in standardised prevalence ratios (SPRs) in Primary Care Trusts (PCT) in England, Health and Social Care Areas (HB) in Northern Ireland, Local Health Boards in Wales (HB) and Health Boards in Scotland (HB) 36
   Case mix in prevalent RRT patients 41
   International comparisons 53
Summary 54

Chapter 3 Demographic and Biochemistry Profile of Kidney Transplant Recipients in the UK in 2011: National and Centre-Specific Analyses 55
Rishi Pruthi, Anna Casula, Iain MacPhee 55

Introduction 56
Transplant activity, waiting list activity and survival data 56
   Introduction 56
   Methods 56
   Results 56
Conclusions 57
<table>
<thead>
<tr>
<th>Chapter 4</th>
<th>Demography of the UK Paediatric Renal Replacement Therapy Population in 2011</th>
<th>81</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rishi Pruthi, Catherine O’Brien, Anna Casula, Fiona Braddon, Malcolm Lewis, Heather Maxwell, Yincent Tse, Carol Inward, Manish D Sinha</td>
<td>Introduction</td>
<td>82</td>
</tr>
<tr>
<td>Methods</td>
<td>82</td>
<td></td>
</tr>
<tr>
<td>Results</td>
<td>82</td>
<td></td>
</tr>
<tr>
<td>Accuracy and completeness of data returns</td>
<td>82</td>
<td></td>
</tr>
<tr>
<td>The UK paediatric prevalent ERF population in 2011</td>
<td>82</td>
<td></td>
</tr>
<tr>
<td>Modality of treatment</td>
<td>84</td>
<td></td>
</tr>
<tr>
<td>Cause of ERF</td>
<td>84</td>
<td></td>
</tr>
<tr>
<td>The UK incident paediatric ERF population in 2011</td>
<td>85</td>
<td></td>
</tr>
<tr>
<td>Trends in ERF demographics</td>
<td>86</td>
<td></td>
</tr>
<tr>
<td>Pre-emptive transplantation</td>
<td>88</td>
<td></td>
</tr>
<tr>
<td>Transfer of patients to adult renal services in 2011</td>
<td>89</td>
<td></td>
</tr>
<tr>
<td>Survival of children on RRT during childhood</td>
<td>89</td>
<td></td>
</tr>
<tr>
<td>Mortality data in 2011</td>
<td>90</td>
<td></td>
</tr>
<tr>
<td>Discussion</td>
<td>91</td>
<td></td>
</tr>
<tr>
<td>Data completeness</td>
<td>91</td>
<td></td>
</tr>
<tr>
<td>Incidence, prevalence and trends</td>
<td>91</td>
<td></td>
</tr>
<tr>
<td>Treatment modality of ERF and observed trends 1997–2011</td>
<td>91</td>
<td></td>
</tr>
<tr>
<td>Pre-emptive transplantation</td>
<td>91</td>
<td></td>
</tr>
<tr>
<td>Comorbidities</td>
<td>91</td>
<td></td>
</tr>
<tr>
<td>Causes of ERF and observed trends 1997–2011</td>
<td>91</td>
<td></td>
</tr>
<tr>
<td>Transfer out and survival data</td>
<td>91</td>
<td></td>
</tr>
</tbody>
</table>

| Chapter 5 | Survival and Causes of Death of UK Adult Patients on Renal Replacement Therapy in 2011: National and Centre-Specific Analyses | 93 |
| Retha Steenkamp, Catriona Shaw, Terry Feest | Introduction | 93 |
| Methods | 93 |
| Results | 93 |
| Discussion | 93 |
| Data completeness | 93 |
| Incidence, prevalence and trends | 93 |
| Treatment modality of ERF and observed trends 1997–2011 | 93 |
| Pre-emptive transplantation | 93 |
| Comorbidities | 93 |
| Causes of ERF and observed trends 1997–2011 | 93 |
| Transfer out and survival data | 93 |
Introduction
Methods
Results of incident (new RRT) patient survival
  Comparison of survival between UK countries
  Modality
  Age
  Gender
  Change in survival on renal replacement therapy by vintage
  Analysis of centre variability in 1 year after 90 days survival
  Analysis of the impact of adjustment for comorbidity on the 1 year after 90 day survival
  Survival in patients with diabetes
  Standard primary renal disease and survival
Results of prevalent patient survival analyses
  One year survival of prevalent dialysis patients by centre
  The one year death rate in prevalent dialysis patients in the 2010 cohort by age group
  One year survival of prevalent dialysis patients by UK country, 1999 to 2010 cohort
  One year survival of prevalent dialysis patients with a primary diagnosis of diabetes, 2001 to 2010 cohort years
  Death rate on RRT compared with the UK general population
Results of analyses on causes of death
  Data completeness
  Causes of death in incident RRT patients
  Causes of death in prevalent RRT patients in the 2010 cohort
  Median life expectancy on RRT

Chapter 6  Haemoglobin, Ferritin and Erythropoietin Amongst UK Adult Dialysis Patients in 2011: National and Centre-Specific Analyses
Anirudh Rao, Julie Gilg, Andrew Williams

Introduction
Methods
Results
Anaemia management in incident dialysis patients
Anaemia management in prevalent dialysis patients
Success with guideline compliance
Discussion

Chapter 7  Clinical, Haematological and Biochemical Parameters in Patients Receiving Renal Replacement Therapy in Paediatric Centres in the UK in 2011: National and Centre-Specific Analyses
Rishi Pruthi, Heather Maxwell, Anna Casula, Fiona Braddon, Malcolm Lewis, Catherine O’Brien, Vincent Tse, Carol Inward, Manish D Sinha

Introduction
Methods
Statistical analyses
Standards
Anthropometry
Blood pressure
Anaemia
Calcium, phosphate and parathyroid hormone (PTH) levels
Appendix C  Renal Services Described for Non-Physicians

The role of the kidneys
Kidney diseases
Acute kidney injury
Chronic kidney disease (CKD) and established renal failure (ERF)
Causes of CKD
Prevention and management
Complications and comorbidity
Renal replacement therapy
Renal dialysis
Haemodialysis
Peritoneal dialysis
Renal transplantation
Nature of renal services

Appendix D  Methodology used for Analyses of PCT/HB Incidence and Prevalence Rates
and of Standardised Ratios

Patients
Years used
Appendix E  Methodology for Estimating Catchment Populations of Renal Centres in England for Dialysis Patients

Appendix F  Additional Data Tables for 2011 New and Existing Patients

Appendix G  UK Renal Registry Dataset Specification

Appendix H  Coding: Ethnicity, EDTA Primary Renal Diagnoses, EDTA Causes of Death

Appendix I  Acronyms and Abbreviations used in the Report

Appendix J  Laboratory Conversion Factors

Appendix K  Renal Centre Names and Abbreviations used in the Figures and Data Tables