18th Annual Report

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Foreword

Established in 1995 by the Renal Association, the UK Renal Registry (UKRR) currently collects data from 71 adult and 13 paediatric kidney centres. The annual report, funded by a small capitation fee, provides a snapshot of centre performance across the UK and is used as a source document for audit and benchmarking against quality of care standards. The collection, validation, analysis and publication of these data requires a great deal of work by the UKRR team and we are indebted to all the staff for their contributions to this 18th Annual Report. This report primarily covers activities in 2014, with centre comparisons including survival data de-anonymised.

When I last wrote the introduction for the UKRR report four years ago, I commented on the growing range of activities that the UKRR was supporting, including the National Registry for Rare Diseases (RaDaR), PatientView (PV), the Acute Kidney Injury Programme ('Think Kidneys') and The UK Renal Data Collaboration (UK RDC). These projects have continued to develop under the watchful eye of Ron Cullen, Chief Executive with support and strategic input from Fergus Caskey, Medical Director, Hilary Doxford, Head of Business and Development and Karen Thomas, Head of Programmes. This growth beyond the ‘core business’ continues apace with the UKRR now contributing to research studies such as the Surveying People Experiencing young Adult Kidney failure (SPEAK) project. There are also plans for the UKRR to provide follow-up data on patients recruited into cohort studies and clinical trials in the near future.

Having made an important contribution to data collection over the last 20 years, it seems logical that the UKRR should become involved in the Kidney Quality Improvement Partnership (KQuIP). This multi-professional initiative, agreed by the whole renal community in the Kidney Health: Delivering Excellence document, aims to improve the quality of care delivered, reduce variation and improve patient outcomes by spreading best practice. As a key partner, the UKRR will act as the data and analysis resource, providing logistic support and a learning platform.

Although the UKRR has secured grant funding for some of these additional activities, long-term sustainability will require an increase in regular income from capitation fees. For the past five years the capitation fee has been £21.50 per patient, levied as separate fees for the UKRR and PatientView on dialysis and transplant patients and representing less than 0.08% of the average annual cost of treating these patients. An increase to £30 per patient has recently been proposed and agreed by NHS England, thus securing the UKRR’s contribution to these important projects into the future.

David Wheeler
Chair, UK Renal Registry Renal Information Governance Board
Chapters and appendices

UK Renal Registry 18th Annual Report: Introduction

Chapter 1 UK Renal Replacement Therapy Incidence in 2014: National and Centre-specific Analyses

Chapter 2 UK Renal Replacement Therapy Prevalence in 2014: National and Centre-specific Analyses

Chapter 3 Demographic and Biochemistry Profile of Kidney Transplant Recipients in the UK in 2014: National and Centre-specific Analyses

Chapter 4 Demography of the UK Paediatric Renal Replacement Therapy Population in 2014

Chapter 5 Survival and Cause of Death in UK Adult Patients on Renal Replacement Therapy in 2014: National and Centre-specific Analyses

Chapter 6 Comorbidities and Current Smoking Status amongst Patients starting Renal Replacement Therapy in England, Wales and Northern Ireland from 2013 to 2014

Chapter 7 Adequacy of Haemodialysis in UK Adult Patients in 2014: National and Centre-specific Analyses

Chapter 8 Haemoglobin, Ferritin and Erythropoietin amongst UK Adult Dialysis Patients in 2014: National and Centre-specific Analyses

Chapter 9 Biochemical Variables amongst UK Adult Dialysis Patients in 2014: National and Centre-specific Analyses

Chapter 10 Clinical, Haematological and Biochemical Parameters in Patients Receiving Renal Replacement Therapy in Paediatric Centres in the UK in 2014: National and Centre-specific Analyses

Chapter 11 2014 Multisite Dialysis Access Audit in England, Northern Ireland and Wales and 2013 PD One Year Follow-up: National and Centre-specific Analyses

Chapter 12 Epidemiology of Reported Infections amongst Patients Receiving Dialysis for Established Renal Failure in England in 2013 to 2014: a Joint Report from Public Health England and the UK Renal Registry

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 CCG/HB Incidence and Prevalence Rates and of Standardised Ratios

Appendix E Methodology for Estimating Catchment Populations of Renal Centres in the UK for Dialysis Patients

Appendix F Additional Data Tables for 2014 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
Contents

UK Renal Registry 18th Annual Report: Introduction
Fergus Caskey, Ron Cullen

Activity since the last Annual Report
The UK Renal Data Collaboration
Changes in eligibility for reporting to the UKRR and the dataset: dialysis and plasma exchange for AKI and CKD stages 4 and 5
National Programmes working with NHS England
Research
Output since the last Annual Report
Completeness of data returns from UK renal centres
Interpretation of centre-specific clinical measures and survival comparisons
Information governance
Conclusion

Chapter 1 UK Renal Replacement Therapy Incidence in 2014: National and Centre-specific Analyses
Julie Gilg, Fergus Caskey, Damian Fogarty

Introduction
Definitions
UK Renal Registry coverage
Renal Association Guidelines
1. Geographical variation in incidence rates
2. Demographics and clinical characteristics of patients starting RRT
3. Late presentation and delayed referral of incident patients
International comparisons
Survival of incident patients
Conclusions
Acknowledgement

Chapter 2 UK Renal Replacement Therapy Prevalence in 2014: National and Centre-specific Analyses
Stephanie J MacNeill, Anna Casula, Catriona Shaw, Clare Castledine

Introduction
Methods
Results
Prevalent patient numbers and changes in prevalence
Prevalent patients by RRT modality and centre
Changes in prevalence
Prevalence of RRT in Clinical Commissioning Groups in England (CCGs), Health and Social Care Areas in Northern Ireland (HBs), Local Health Boards in Wales (HBs) and Health Boards in Scotland (HBs)
Factors associated with variation in standardised prevalence ratios in Clinical Commissioning Groups in England, Health and Social Care Trust Areas in Northern Ireland, Local Health Boards in Wales and Health Boards in Scotland
Chapter 5 Survival and Causes of Death in UK Adult Patients on Renal Replacement Therapy in 2014: National and Centre-specific Analyses

Retha Steenkamp, Anirudh Rao, Simon Fraser

Introduction 112
Methods 112
Results
Incident (new RRT) patient survival 114
Overall survival 114
Survival by UK country 114
Survival by modality 115
Survival by age 115
Age and the hazard of death 117
Survival by gender 117
Survival in the 2004–2013 cohort 117
Long term survival: trends up to 10 years post RRT start 118
Change in survival on RRT by vintage 118
Centre variability in one year after 90 days survival 120
Centre variability in one year after 90 day survival: impact of adjustment for comorbidity 121
Survival in patients with diabetes 122
Survival in prevalent dialysis patients
Overall survival 124
Survival by UK country 124
One year survival of prevalent dialysis patients by centre 125
Survival by age group 125
One year death rate in prevalent dialysis patients in the 2013 cohort by age group 125
Time trends in survival, 2004 to 2013 125
Survival in patients with diabetes 125
Time trends in patients with a primary diagnosis of diabetes 126
Death rate on RRT compared with the UK general population 126
Causes of death
Data completeness 128
Causes of death in incident RRT patients 129
Causes of death within the first 90 days 129
Causes of death within one year after 90 days 129
Cause of death in prevalent RRT patients in the 2013 cohort 130
Conclusion 131
Appendix 1: Survival tables 134
Chapter 6  Comorbidities and Current Smoking Status amongst Patients starting Renal Replacement Therapy in England, Wales and Northern Ireland from 2013 to 2014  
Retha Steenkamp, Fergus Caskey

Introduction 146
Methods 146
Results 147
   Completeness of comorbidity returns from each participating centre 147
   Prevalence of multiple comorbidity 149
   Frequency of each comorbid condition 149
   Prevalence of comorbidity by age group 149
   Prevalence of comorbidity by ethnic origin 150
   Prevalence of comorbidity amongst patients with diabetes mellitus 151
   Late presentation and comorbidity 151
   Age and comorbidity in patients by treatment modality at start of RRT 151
Discussion 153
   Data completeness in the UKRR and the pattern of missing comorbidity data 153
   Improving comorbidity data completeness 153
   Expansion of comorbidity data collected 153

Chapter 7  Adequacy of Haemodialysis in UK Adult Patients in 2014: National and Centre-specific Analyses  
Andrew Davenport, Catriona Shaw, Retha Steenkamp

Introduction 156
Methods 156
Results 157
   Data completeness 157
   Achieved URR 158
   Changes in URR over time 160
   Variation of achieved URR with time on dialysis 160
Conclusions 165

Chapter 8  Haemoglobin, Ferritin and Erythropoietin amongst UK Adult Dialysis Patients in 2014: National and Centre-specific Analyses  
Julie Gilg, Anirudh Rao, Andrew J Williams

Introduction 170
Methods 170
Results 171
   Anaemia management in incident dialysis patients 171
   Anaemia management in prevalent dialysis patients 175
Conclusions 193

Chapter 9  Biochemical Variables amongst UK Adult Dialysis Patients in 2014: National and Centre-specific Analyses  
Johann Nicholas, Rebecca Evans, Catriona Shaw, Anne Dawnay

Introduction 196
Methods 196
Results 198
   Mineral and bone variables 198
Chapter 10  Clinical, Haematological and Biochemical Parameters in Patients Receiving Renal Replacement Therapy in Paediatric Centres in the UK in 2014: National and Centre-specific Analyses

Alexander J Hamilton, Fiona Braddon, Anna Casula, Carol Inward, Malcolm Lewis, Tamara Mallett, Heather Maxwell, Catherine O’Brien, Vincent Tse, Manish D Sinha

Introduction 238
Methods 238
Results 239
  Data completeness 239
  Growth 239
  Cardiovascular risk factor evaluation 244
  Laboratory and clinical indices – quarterly data 246
  Laboratory and clinical indices – annual data 247
Discussion 249
  Quarterly data 249
  Highlights from the 2014 data 249
  Future work 250
Acknowledgement 250

Chapter 11  2014 Multisite Dialysis Access Audit in England, Northern Ireland and Wales and 2013 PD One Year Follow-up: National and Centre-specific Analyses

Anirudh Rao, Rebecca Evans, Martin Wilkie, Richard Fluck, Mick Kumwenda

Introduction 254
Methods 254
Results 254
  Inclusion and exclusion criteria 254
  Data completeness 255
  Variations in first dialysis access 255
  First dialysis access by renal centre 260
  First dialysis access and referral time 260
  First dialysis access and surgical assessment 262
  Dialysis access at three months after starting RRT 267
  2013 PD access audit one-year follow-up 271
Conclusions 275
Acknowledgement 277

Chapter 12  Epidemiology of Reported Infections amongst Patients Receiving Dialysis for Established Renal Failure in England 2013 to 2014: a Joint Report from Public Health England and the UK Renal Registry

Rebecca Evans, Fergus Caskey, Richard Fluck, Lisa Crowley, John Davies, Olisaeloka Nsonwu, Ken Farrington

Introduction 280
Methods 280