

The EVEREST study: an international collaboration*

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Abstract

Rates of initiation of renal replacement therapy (RRT), use of home modalities of treatment and patient outcomes vary considerably between countries. This paper reports the methods and baseline characteristics of countries participating in the EVEREST study ($n = 46$), a global collaboration examining the association between medical and non-medical factors and RRT incidence, modality mix and survival. Numbers of incident and prevalent patients were collected for current (2003–05) and historic (1983–85, 1988–90, 1993–95 and 1998–2000) periods stratified, where available, by age, gender, treatment modality and cause of end stage renal disease (diabetic *versus* non-diabetic). General population age and health indicators and national-level macroeconomic data were collected from secondary data sources. National experts provided primary data on renal service funding, resources and organization. The median (inter quartile range) RRT incidence per million of the population (pmp) was 130 pmp (102–167 pmp). The general population life expectancy at 60 was 22.1 years (19.7–23.1 years) and 6.9% had diabetes mellitus (5.4–9.0%). Healthcare spending as a percentage of gross domestic product was 8.1% (5.6–9.3%). Countries averaged nine dialysis facilities pmp (4–12 pmp), with 69.0% (43.9–99.0%) owned by the public or private not-for-profit sector. The number of nephrologists ranged from 0.5 to 48 pmp (median 12 pmp). The heterogeneity of EVEREST countries will enable modelling to examine the independent association between medical and non-medical factors on RRT epidemiology.

Keywords: dialysis; epidemiology and outcomes; risk factors

Introduction

Chronic kidney disease (CKD) consistently affects 10–15% of the general population [1–4] yet the incidence of renal replacement therapy (RRT) varies from around 100–120 per million of the population (pmp) in the UK, Australia, New Zealand and the Netherlands to 350–450 pmp in Jalisco (Mexico), Taiwan and the United States of America [5]. Variation in rates of progression of CKD to end-stage renal disease (ESRD) may explain some of these differences [3], but other factors such as referral to renal services [6,7], the decision to initiate dialysis [8] and availability of resources [9] are also likely to have played a part. There also seem to be associations with national wealth, spending on health care and health care system organization [10,11].

Considering patients on RRT, the proportion of patients receiving each modality of treatment—haemodialysis (HD), peritoneal dialysis (PD) and transplantation—shows marked variation around the world. In 2006, around 80% of prevalent patients were receiving PD in Hong Kong and Jalisco (Mexico) compared with less than 5% in Japan, Bangladesh and Luxembourg and rates of home HD ranged from <1% in many countries to 16% in New Zealand [5]. Studies that have previously examined these differences have highlighted the role of health care organization and spending [11–13] as well as the relative cost of staff and consumables [14,15] and physician training [16] and attitudes [17,18].

There also appear to be marked international differences in survival on dialysis [19], which persist after adjustment for casemix [20]. Recognition of the need to understand these differences was the driving force behind the Dialysis Outcomes and Practice Patterns Study (DOPPS) [21]. Although DOPPS is restricted to in-centre haemodialysis, it investigates a large number of potential explanatory variables at the individual level including patient casemix and processes of care. At a broader level, however, the

characteristics of the general population or of the health care system and inequalities in access to renal services [12,22] may also explain some of the variations in RRT survival [23,24].

The EVEREST study (Explaining the Variation in Epidemiology of RRT through Expert opinion, Secondary data sources and Trends over time) aims to examine in a wide range of countries worldwide the influence of medical and non-medical factors on (1) current RRT incidence, (2) changes in RRT incidence over time, (3) RRT modality mix and (4) survival on RRT and to attempt for the first time to quantify the strength of any associations that persist after adjusting for differences in casemix. This paper describes the methods that have been adopted to collect the study data and describes the baseline characteristics of the participating countries.

Methods

Primary and secondary data have been collected as part of the study—primary data on renal service organization, funding and resources and secondary data on population age and health indicators, macroeconomic indicators and RRT epidemiology.

All renal registries that were known to have reported data on the epidemiology of RRT at a national level were approached and invited to take part in the study. If national-level data were not available regional registries were approached. For reasons partly related to concerns about independence of the observations and partly related to availability of macroeconomic data, the study group decided at its first meeting to adopt a strict policy of including only one observation for each country. This was despite logical arguments for some countries—such as the UK, Spain, Italy, Belgium, the USA—that regional differences exist that will be lost if analysis is done at too high a level. Local approval was obtained, where appropriate, for collaboration in the study.

Dependent variables—incidence of RRT, treatment modality and patient survival

Renal registry data were collected in two ways:

- Some renal registries were annually submitting individual patient data to the ERA-EDTA Registry in Amsterdam at the time of data collection (Table 1). For these countries it was only necessary to inform the registries of the plan to undertake the study and ask for their collaboration; but no additional renal registry data collection was required.
- For renal registries not routinely providing individual patient data to the ERA-EDTA Registry, incidence, prevalence and population data were collected specifically for the study in an electronic spreadsheet with cross-checks built in to optimize accuracy and consistency of the data. Data were collected in five gender-specific age-bands (0–19, 20–44, 45–64, 65–74 and ≥ 75 years). Where data were not available at this level they were collected in two age-bands (<65 and ≥ 65 years) or non-stratified.

Data were collected (where available) for five study periods: 1983–1985, 1988–1990, 1993–1995, 1998–2000 and 2003–2005. Three-year study periods were chosen to ensure stability of measurements. Incidence of RRT was defined as the number of patients commencing RRT for the first time during the study period and prevalence as the number of patients alive on RRT on 31st December of the mid-year of the study period. Total incidence of RRT and incidence of RRT for ESRD secondary to diabetic nephropathy were collected at Day 1, although it should be noted that not all registries capture patients commencing RRT with a pre-emptive transplant (Table 1). Data on RRT modality mix were collected for incident patients alive on RRT 91 days after the initiation of RRT (HD, PD and renal transplant) and prevalent patients alive on RRT on 31st December of the mid-year of the study period (centre HD, home HD, PD and renal transplant). Registries also provided age-gender stratified data for the

covered general population. For each study period, incidence rates and prevalence pmp were calculated by dividing the sum of the observed counts during the study period by the sum of the covered general population in this study period.

For registries with individual patient data, survival tables (using Kaplan Meier) were collected for patients alive and still requiring RRT 91 days after the initiating treatment in the study period 2003–2005, with follow-up to 31st December 2006. Separate survival tables were collected for individuals under and over 65 years of age and those with and without diabetes as the cause of ESRD. All survival tables were also collected separately with and without censoring for transplantation.

Independent variables

A list of potential independent (explanatory) variables was created following a review of the literature and discussions with colleagues working in different health care systems around the world. A *rationale* for each variable was stated *a priori* and where possible referenced. Three broad groups of data were identified:

General population indicators. General population age and health indicator data were collected from secondary data sources (Box 1). If data were unavailable from these secondary sources for any item, the collaborating renal registry was approached and asked for guidance in obtaining the data from the respective national office of statistics. With the exception of diabetes mellitus prevalence, for which only one estimate was available, data were collected for each of the five 3-year study periods (see above) and the average taken to derive a single variable for each 3-year study period.

Macroeconomic indicators. National-level macroeconomic data were collected from a number of international secondary data sources (Box 1) or, with the assistance of the collaborating renal registry, from the respective offices of national statistics.

One of the indicators, the United Nations Development Programme Human Development Index (HDI), was collected based on a prior belief that the association between independent variables and RRT incidence was likely to be related to a nation's state of economic and social development. For three variables—the WHO Responsiveness Index, the Gini Coefficient and the HDI—only one measure was collected for the current study period and none were collected for the historic study periods. For the other macroeconomic variables, data were collected for each of the five 3-year study periods (see above) and the average taken to derive a single variable for each 3-year study period.

Renal service organization indicators. Although some of the renal service variables (Box 2) were routinely collected by state healthcare administrations or professional organizations, locating these data and judging their validity required local knowledge and expertise. Further, many of the renal service variables were not routinely collected or required an element of nation-specific expert opinion. For these reasons it was decided that an expert would be needed in each country to assist in the collection of these data.

National experts were identified through national renal registries usually with approval by the relevant national society of nephrology. The initial correspondence to the collaborating renal registry advised that the national expert would need considerable experience in renal service provision and planning at a high level, to be able to locate and collect the required data and be able to give responses at a national level. As we were collecting historical data (back to 1983) it was felt that the national expert needed to have been working in nephrology for at least 20 years.

A questionnaire (English language) was developed to collect the national expert data. This was piloted in the UK, modified slightly and then further piloted in The Netherlands and Romania. National experts were then allocated to an EVEREST co-investigator (ACo, ACu, AM, BS, FC or KJ) to work with them to complete the questionnaire through a combination of telephone meetings and email correspondence. Where possible, EVEREST co-investigators were matched to national experts who spoke their first language.

It was recognized that having the study formally approved might optimize response rates and this was achieved at a global level through official endorsement of the study by both the European Renal Association-European Dialysis and Transplantation Association (ERA-EDTA) and the International Society of Nephrology (ISN).

Table 1. Availability of current (2003–2005) and historic (1983–1985, 1988–1990, 1993–1995, 1998–2000) age- and gender-stratified renal registry data

Country	Routinely reported individual-level data to ERA-EDTA; Registry at time of data collection?	Availability of age and gender stratified data for the period 2003–2005 (number of age bands [†])				
		RRT incidence	RRT incidence due to DN	RRT modality mix	RRT survival	Earliest period RRT incidence data available
Argentina	No	5 ^a	5	1 ^{b,c}	Yes	98–00 ^d
Australia	No	5	5	5	Yes	83–85
Austria	Yes	5	5	5	Yes	83–85
Bangladesh	No	5 ^{a,c,e}	NA	1 ^{b,c}	No	98–00
Belgium	Yes	5	5	5	Yes	98–00
Bosnia-Herzegovina	No	5 ^a	5	5	No	03–05 only
Canada	No	5	5	5	Yes	83–85
Chile	No	2 ^{a,c,e}	NA	1 ^c	No	98–00
Croatia	No	5	5	5	No	03–05 only
Czech Republic	No	1 ^{a,c,e}	5 ^c	1 ^c	No	93–95
Denmark	Yes	5	5	5	Yes	93–95
Estonia	No	1 ^{c,e}	NA	1 ^{b,c}	No	03–05 only
Germany	No	5	5	2	No	03–05 only
Finland	Yes	5	5	5	Yes	83–85
France	No	5	5	5	Yes	03–05 only
FYR Macedonia	No	5	5	5	No	03–05 only
Greece	Yes	5	5	5	Yes	83–85
Hungary	No	5 ^{a,c}	5 ^c	1 ^{b,c}	No	83–85 ^d
Iceland	Yes	5	5	5	Yes	83–85
Israel	No	5	5	5	No	88–90
Italy	Yes	5	5	5	No	03–05 only
Japan	No	5 ^a	5	5	Yes	83–85
Luxembourg	No	2 ^c	NA	2 ^c	No	83–85 ^d
Malaysia	No	5	5	5	No	83–85
Mexico, Jalisco	No	1 ^{a,c}	1 ^c	1 ^{b,c}	No	98–00
Netherlands	Yes	5	5	5	Yes	83–85
New Zealand	No	5	5	5	Yes	83–85
Norway	Yes	5	5	5	Yes	83–85
Peru	No	5 ^a	5	NA	No	98–00
Philippines	No	5 ^a	5	NA	No	98–00
Poland	No	5 ^c	1 ^c	1 ^{b,c}	No	83–85 ^d
Portugal	No	1 ^{a,f}	NA	NA	No	98–00
Republic of Korea	No	1 ^c	1 ^c	1 ^c	No	83–85
Romania	No	5	5	5	Yes	03–05 only
Russia	No	5 ^{a,c}	NA	5 ^b	No	03–05 only
Slovenia	No	5	2	2	Yes	03–05 only
Spain	No	5	5 ^c	5	Yes	83–85 ^d
Sweden	Yes	5	5	5	Yes	93–95
Taiwan	No	5 ^a	5	5	Yes	88–90
Thailand	No	1 ^{c,e}	1 ^c	1 ^c	No	98–00
Tunisia	No	5 ^{a,e}	5	5	No	83–85
Turkey	No	5 ^a	5	5	No	93–95 ^d
UK	Yes	5	5	5	Yes	98–00
USA	No	5	5	5	No	83–85
Uruguay	No	5 ^a	5	5	Yes	83–85
Venezuela	No	2	2	2	No	03–05 only

[†]Number of age bands: 1 = not stratified, all ages grouped together, 2 = <65 and 65+, 5 = 0–19, 20–44, 45–64, 65–74, 75+.

^aDialysis patients only.

^bData available for prevalent patients only.

^cData not available stratified by gender.

^dNot all data available for all periods.

^eIncidence of RRT at Day 30 (Republic of Korea) or Day 91 (Bangladesh, Chile, Czech Republic, Estonia, Thailand and Tunisia).

^fPer million population data only.

DN = diabetic nephropathy.

Six items to be collected by the national experts were considered difficult to capture and particularly sensitive to personal opinion. For those items Likert scale-style questions were included in the national expert questionnaire to provide a semi-quantitative way of measuring these variables (Box 2). The answering mode to these questions took the form of a horizontal line, on which the respondent would indicate his or her re-

sponse by checking 1 of 10 tick boxes from 0 to 10. These responses were subsequently categorized into rarely (0–1), sometimes (2–8) and often (9–10). When a national expert felt unable to provide a single, national-level response for one of these Likert scale-style questions, he or she arranged for short regional questionnaires (containing the six region-specific Likert scale-style questions) to be completed by one or more regional expert(s).

Box 1. Definition, *rationale* and source of general population and macroeconomic indicators

Variable	Description	Source
Population age and health indicators		
% population above 65	The percentage of the general population older than 65 years. <i>Rationale:</i> RRT incidence is much higher in the elderly; countries with populations that are skewed towards the elderly would be expected to have higher RRT incidence	U.S. Census Bureau: International Data Bases (IDB) 'Midyear Population by Age and Sex'
Life expectancy at 60	The number of years an individual aged 60 would be expected to live. <i>Rationale:</i> This is being used as a surrogate for competing risk, i.e. death prior to developing ESRD. If true, and all other things being equal, countries with lower life expectancy at 60 would be expected to have a lower RRT incidence rate	EUROSTAT data for EU countries. OECD data for other OECD countries. National data for Argentina, Chile, Israel, Jalisco, Russia, Thailand, Uruguay, Venezuela. Not available for remaining countries
Diabetes prevalence	The percentage of the general population aged 20–79 estimated to have diabetes mellitus or impaired glucose tolerance. <i>Rationale:</i> Diabetes mellitus is the cause of ESRD in 17–55% of incident RRT patients; assuming equal rates of development of CKD and progression to ESRD, countries with a high prevalence of diabetes mellitus would be expected to have higher rates of RRT incidence	International Diabetes Federation. National rates for each country have not been age-standardized. WHO for Russia. Not available for Tunisia
Cardiovascular mortality rate	Age-gender standardized cardiovascular mortality rates for the general population. <i>Rationale:</i> As a surrogate of cardiovascular disease in a population, this may be expected to be associated with renal vascular disease and hypertension—common causes of ESRD. However, as CV mortality is also a surrogate for competing risk, high CV mortality may be associated with lower rates of ESRD	WHO mortality tables. National data supplied by Belgium, Denmark and Thailand. Not available for Bangladesh, Bosnia and Herzegovina, Malaysia, Peru, the Philippines, Taiwan, Tunisia and Turkey
Macroeconomic indicators		
GDP per capita	Gross domestic product per capita is a measure of national wealth. Data have been collected in US Dollars and adjusted for purchasing power parity. <i>Rationale:</i> GDP per capita is associated with early rate of diffusion of new medical technologies	International Monetary Fund (IMF): World Economic Outlook Database, April 2008. For Jalisco, Mexico, National statistics were used. For countries formerly part of the Soviet Union or Yugoslavia estimates were based on OECD data available and adjusted by calculating growth rates and deflating by these rates to obtain values for 1983–1989
Gini coefficient	The GINI index is a measure of income inequality. <i>Rationale:</i> Countries with a small number of very rich people and a large number of very poor people are likely to have other societal inequities and may therefore have poorer access to health care, poorer preventive/primary care and consequently a higher proportion of ESRD	World Development Indicators, 2007. Data for Iceland, Luxembourg and Taiwan came from the CIA database
Health expenditure as % GDP	Percentage of gross domestic product (i.e. national wealth) spent on health care. <i>Rationale:</i> Countries spending a smaller proportion of GDP on health care are likely to have more control over introduction and expansion of new and expensive medical technologies	WHO HFA database for EU countries. OECD Health Database for OECD countries. WHO SIS database for non-EU and non-OECD countries. Secretaria de Salud for Jalisco, Mexico
Public as % total health expenditure	Public expenditure as a percentage of total expenditure on health care. <i>Rationale:</i> The proportion of health care expenditure that is public (taxes or compulsory social insurances) has been reported to be a proxy for the level of regulatory constraint on adopting and expanding new medical technologies	WHO HFA database for EU countries. OECD Health Database for OECD countries. World Bank NHP Stats for remaining countries. Secretaria de Salud for Jalisco, Mexico
% population covered by health care system	The percentage of the general population covered by the health care system. <i>Rationale:</i> Countries with health care systems that do not provide effective preventive health care (blood pressure/diabetes control) may have higher rates of development and progression of CKD	OECD for OECD countries. National data for Argentina, Bangladesh, Chile, Croatia, Estonia, Iceland, Macedonia, Poland, Russia, Slovenia, Thailand, Uruguay. Not available for remaining countries
WHO responsiveness index	This is a composite indicator of health care system performance developed by the WHO. Countries with a 'more responsive' health care system should have earlier uptake of new technologies	WHO (note, only available for 1999)
Human Development Index	The United Nations Development Programme Human Development Index (HDI) combines indicators of life expectancy, education and income to create a validated composite score of a nations state of development	Available from www.hdr.undp.org

Box 2. National expert variables

Facilities
Number of dialysis facilities
The percentage of haemodialysis facilities owned by the public, private not-for-profit and private for-profit sector†
Restriction on setting up new haemodialysis facilities
Facility reimbursement method (activity based versus global budget)†
Facility reimbursement rates for HD and PD
Staffing
Salaries of dialysis technicians, nurses and doctors
Indicator of nephrologist salary relative to other hospital specialists†
Number of nephrologists (total and WTE)
Renal service
Patient choice between dialysis providers
Competition for patients between dialysis providers
Laws restricting home dialysis†
Likert Scale questions
Distance to haemodialysis centre—as a barrier to RRT†
Distance to haemodialysis centre—as a reason for choosing PD rather than HD†
Non-referral of elderly/co-morbid patients†
Social and cultural attitudes of patients†
Limited resources for haemodialysis†
Active conservative/non-dialysis programme†

Indicators relating to renal service organization and delivery

†Collected for all five study periods. WTE = whole time equivalent.

A national-level score was then calculated by weighting the regional responses according to the proportion of the national population represented by each region.

Statistical analyses

Continuous variables are reported as a median, interquartile range (IQR) and range and categorical variables as the percentage for each category. Statistical analyses were performed using SPSS® version 15.0.

Results

Between July 2008 and February 2009, renal registry data relating to the five study periods were received from 47 of the 54 registries identified as having previously reported RRT epidemiology data. These 47 registries represented 46 countries from around the world (Figure 1).

RRT incidence

The RRT incidence for the period 2003–2005 was 130 pmp (IQR 102–167 pmp, range 12–455 pmp) (Figure 2). For the study period 2003–2005, six countries provided data unstratified for age. The remaining 40 countries provided data stratified into two ($n = 3$) or five age bands ($n = 37$). RRT incidence data for all periods back to 1983–1985 were available for 19 countries (Table 1).

General population and macro-economic indicators

The median percentage of the populations that were aged 65+ was 13.8% (IQR 9.3–16.1%) with an annual cardiovascular mortality in this subgroup of 1.9% (IQR 1.0–2.3%) (Table 2). Overall life expectancy at 60 was 22.1 years (IQR 19.7–23.1 years) and diabetes mellitus was prevalent

Table 2. Summary of the general population and macroeconomic data

	All countries ($n = 46$) Median (IQR)
Life expectancy at 60 (years)	22.1 (19.7–23.1)
Diabetes prevalence (%)	6.9 (5.4–9.0)
Cardiovascular mortality rate	
All (%)	0.30 (0.14–0.45)
65+ (%)	1.87 (1.05–2.34)
GDP per capita (in USD)	20 706 (9842–30 203)
Gini coefficient	34.4 (28.4–40.1)
Health exp as % GDP (%)	8.1 (5.6–9.3)
Public as % total health exp (%)	70.9 (50.8–80.5)
WHO responsiveness index	6.1 (5.5–6.9)

in 6.9% (IQR 5.4–9.0%) of individuals aged 20–79 years (Table 2). A wide distribution in the macroeconomic indicators was also observed (Table 2).

Renal services organization indicators

Countries had an average of nine dialysis facilities pmp (IQR 4–12 pmp), with a median of 69% owned by the public or private not-for-profit sector. The decision to set up a new haemodialysis facility was controlled in some way by the state in 52% of countries—in 11% the decision was based on an assessment of need and in 41% it was based on availability of funding. National experts reported high levels of perceived competition for patients between centres in 41% of countries and high levels of perceived choice of dialysis facility amongst patients in 52% of countries. The number of whole time equivalent nephrologists ranged from 0.5 to 48 pmp (median 12 pmp). Nephrologists were considered to earn, on average, at least 25% more than non-renal hospital specialists in 35% of countries (and at least 25% less in 4% of countries).

Non-referral of elderly, co-morbid patients to a nephrologist was considered ‘rare’ in 39% of countries. Distance from a dialysis facility was reported as ‘sometimes’ a reason for choosing PD rather than HD in 67% of countries and in elderly co-morbid patients distance was reported as ‘sometimes’ a reason for choosing not to have dialysis in 39% of countries. Access to haemodialysis was reported as ‘sometimes’ or ‘often’ restricted due to lack of haemodialysis facilities in 33% and 6% of countries, respectively.

Discussion

To date, efforts to understand the worldwide variation in RRT incidence have relied on qualitative work describing the factors and policies that may have influenced RRT treatment rates. Various perspectives have been taken. In the 1990s, De Vecchi adopted a top-down approach with measures of health care spending and health care organization from a number of industrially developed countries [10]. More recently, a broader and more detailed, but still descriptive, approach was applied to the 12 DOPPS countries by its health economics subgroup [25]. An alternative approach, systematically targeting the various stages in the pathway towards receiving RRT, was adopted in a study



Fig. 1. Map of countries participating in the EVEREST study.

exploring the reasons behind the higher RRT incidence in Germany compared to England and Wales [26]. While such approaches provide interesting anecdotes and can be hypothesis generating, they are unable to comment on the relative importance of individual medical or non-medical factors—for this, quantitative data for each potential explanatory factor, collected in a large number of countries, are required.

The EVEREST study takes such a systematic approach, collecting quantitative data for a broad range of countries worldwide. By simultaneously collecting general population age and health indicators and macroeconomic measures alongside quantitative data on renal service organization and resources, it will be possible to study which of the variables collected have the strongest effect on the study outcomes having adjusted for relevant confounders.

The countries included in EVEREST are markedly heterogeneous in their RRT incidence, general population demographics and macroeconomic statistics as well as in the organization of their renal services and availability of resources. This heterogeneity is important as it will improve the power of the study in multivariate model building. Historical data, which will provide further heterogeneity, will be important for two reasons. Firstly, a country's current RRT incidence is likely to be influenced by previous health policy and resource availability. And secondly, the influence of non-medical factors on adoption of medical technologies

is likely to evolve over time and at different rates depending on a nation's wealth and health care spending [27]. To be able to examine this, EVEREST has collected data for many items going back to 1983.

The high response rate from registries and national experts in renal services is testament to the international interest there is in understanding the marked differences in RRT epidemiology. Although many of the national expert variables were purely quantitative (e.g. number of nephrologists, numbers of dialysis units, costs, reimbursement rates and salaries), a small number attempted to capture quantitative elements that were related to process (e.g. how much control the state has over setting up a new dialysis facility and how much competition there was between dialysis providers).

The six Likert scale questions attempted to capture more complex situations such as healthcare seeking behaviour and access to healthcare (e.g. non-referral of elderly, comorbid patients to renal services) to which the replies could only be semi-quantitative. While the Study group recognized from the outset that a single individual's attempt to summarize these national-level system characteristics was potentially of limited validity, it was considered important to explore these areas to keep them on the research agenda. The experience gained in this attempt will be useful when designing future studies. However, given the uncertainty about the validity of the responses it is unlikely that these

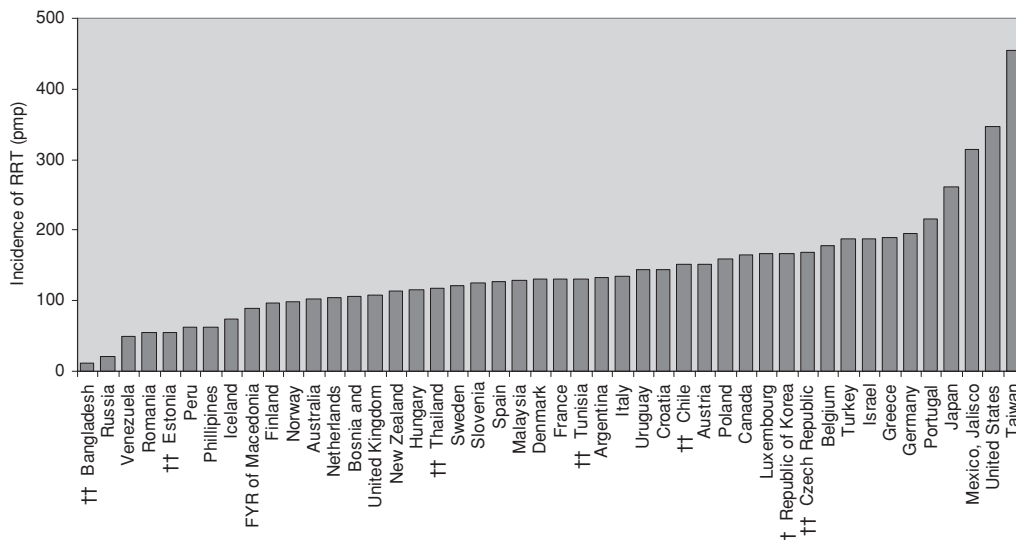


Fig. 2. Incidence of RRT at Day 1 for the period 2003–2005 in countries participating in the EVEREST study. †RRT incidence at Day 30; ††RRT incidence at Day 91.

data items will be included in any of the main EVEREST models.

Supplementary free-text data (from notes made during interviews or added by national experts) collected alongside the quantitative data, although difficult to analyse, will provide invaluable depth and validity to the findings and provide an opportunity to identify factors not previously considered.

The EVEREST dataset has been collected primarily to provide insight into the role that non-medical factors play in explaining the worldwide variation in current RRT incidence, changes in RRT incidence over time, RRT modality mix and RRT survival. These analyses are likely to identify factors that are worthy of closer scrutiny. The study has already demonstrated the willingness of nephrologists and renal registries to collaborate on an international scale in order to resolve potential inequity in access to and outcomes on RRT.

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Conflict of interest statement. None declared.

Appendix 1. Renal registry collaborators and national experts

- Australia: Renal registry collaborator—Dr Stephen McDonald and Dr Andrew Brunskill, ANZDATA Registry, Adelaide, Australia. National expert—Prof. Rowan Walker, Royal Melbourne Hospital, Australia.
- Austria: Renal registry collaborator and national expert—Dr Reinhard Kramar, Austrian Dialysis and Transplant Registry, Austria.
- Bangladesh: Renal registry collaborator and national expert—Dr Harun ur Rashid, Professor and Chairman, BSM Medical University and President, Bangladesh Renal association.
- Belgium (Dutch-speaking): Renal registry collaborator—Hans Augustijn, Nederlandstalige Belgische Vereniging voor Nefrologie, Edegem, Belgium. National expert—Dr Jean-Marie Billioux, President of the Board, Dutch-speaking Belgian Society of Nephrology (NBVN), Belgium.
- Belgium (French-speaking): Renal registry collaborator and national expert—Prof. Frédéric Collart, CHU Brugmann, Belgium and Groupement des Néphrologues Francophones de Belgique (GNFB), Bruxelles, Belgium.
- Bosnia and Herzegovina: Renal registry collaborator and national expert—Prof. Halima Resić, Clinic for Haemodialysis, University of Sarajevo and Renal Registry of Bosnia and Herzegovina.
- Canada: Renal registry collaborator—Robert Williams, CORR—Canadian Institute for Health Information, Toronto, Canada. National expert—Prof. Adeera Levin, British Columbia Provincial Renal Agency and University of British Columbia, Canada.
- Chile: Renal registry collaborator and national expert—Prof. Dr. Hugo Poblete Badal, Chilean Renal Registry, Chilean Society of Nephrology, Hospital Carlos Van Buren, Valparaíso and Universidad de Valparaíso, Escuela de Medicina, Valparaíso, Chile.
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References

1. Chadban SJ, Briganti EM, Kerr PG *et al.* Prevalence of kidney damage in Australian adults: the AusDiab kidney study. *J Am Soc Nephrol* 2003; 14: S131–S138
2. Drey N, Roderick P, Mullee M *et al.* A population-based study of the incidence and outcomes of diagnosed chronic kidney disease. *Am J Kidney Dis* 2003; 42: 677–684
3. Hallan SI, Coresh J, Astor BC *et al.* International comparison of the relationship of chronic kidney disease prevalence and ESRD risk. *J Am Soc Nephrol* 2006; 17: 2275–2284
4. Coresh J, Selvin E, Stevens LA *et al.* Prevalence of chronic kidney disease in the United States. *JAMA* 2007; 298: 2038–2047
5. U.S. Renal Data System. USRDS 2008 Annual Data Report: Atlas of End-Stage Renal Disease in the United States. National Institute of Diabetes and Digestive and Kidney Diseases, 2008
6. Sekkarie M, Cosma M, Mendelssohn D. Nonreferral and nonacceptance to dialysis by primary care physicians and nephrologists in Canada and the United States. *Am J Kidney Dis* 2001; 38: 36–41
7. Challah S, Wing AJ, Bauer R *et al.* Negative selection of patients for dialysis and transplantation in the United Kingdom. *Br Med J (Clin Res Ed)* 1984; 288: 1119–1122
8. McKenzie JK, Moss AH, Feest TG *et al.* Dialysis decision making in Canada, the United Kingdom, and the United States. *Am J Kidney Dis* 1998; 31: 12–18
9. Audit in renal failure; the wrong target? *Br Med J (Clin Res Ed)* 1981; 283: 261–262
10. De Vecchi AF, Dratwa M, Wiedemann ME. Healthcare systems and end-stage renal disease (ESRD) therapies—an international review: costs and reimbursement/funding of ESRD therapies. *Nephrol Dial Transplant* 1999; 14: 31–41
11. Grassmann A, Gioberge S, Moeller S *et al.* ESRD patients in 2004: global overview of patient numbers, treatment modalities and associated trends. *Nephrol Dial Transplant* 2005; 20: 2587–2593
12. Horl WH, de Alvaro F, Williams PF. Healthcare systems and end-stage renal disease (ESRD) therapies—an international review: access to ESRD treatments. *Nephrol Dial Transplant* 1999; 14(Suppl 6): 10–15
13. MacGregor MS, Agar JWM, Blagg CR. Home haemodialysis—international trends and variation. *Nephrol Dial Transplant* 2006; 21: 1934–1945
14. Wordsworth S, Ludbrook A, Caskey F *et al.* Collecting unit cost data in multicentre studies. Creating comparable methods. *Eur J Health Econ* 2005; 6: 38–44
15. Just PM, de Charro FT, Tschosik EA *et al.* Reimbursement and economic factors influencing dialysis modality choice around the world. *Nephrol Dial Transplant* 2008; 23: 2365–2373
16. Finkelstein FO. Structural requirements for a successful chronic peritoneal dialysis program. *Kidney Int Suppl* 2006; S118–S121
17. Jung B, Blake PG, Mehta RL *et al.* Attitudes of Canadian nephrologists toward dialysis modality selection. *Perit Dial Int* 1999; 19: 263–268
18. Mendelssohn DC, Mullaney SR, Jung B *et al.* What do American nephrologists think about dialysis modality selection? *Am J Kidney Dis* 2001; 37: 22–29
19. Held PJ, Brunner F, Odaka M *et al.* Five-year survival for end-stage renal disease patients in the United States, Europe, and Japan, 1982 to 1987. *Am J Kidney Dis* 1990; 15: 451–457
20. Marcelli D, Stannard D, Conte F *et al.* ESRD patient mortality with adjustment for comorbid conditions in Lombardy (Italy) versus the United States. *Kidney Int* 1996; 50: 1013–1018
21. Young EW, Goodkin DA, Mapes DL *et al.* The Dialysis Outcomes and Practice Patterns Study (DOPPS): an international hemodialysis study. *Kidney Int* 2000; 57: S74–S81
22. Lameire N, Van Biesen W. The pattern of referral of patients with end-stage renal disease to the nephrologist—a European survey. *Nephrol Dial Transplant* 1999; 14(Suppl 6): 16–23
23. van Dijk PC, Zwinderman AH, Dekker FW *et al.* Effect of general population mortality on the north-south mortality gradient in patients on replacement therapy in Europe. *Kidney Int* 2007; 71: 53–59
24. Yoshino M, Kuhlmann MK, Kotanko P *et al.* International differences in dialysis mortality reflect background general population atherosclerotic cardiovascular mortality. *J Am Soc Nephrol* 2006; 17: 3510–3519
25. Dor A, Pauly MV, Eichleay MA *et al.* End-stage renal disease and economic incentives: the International Study of Health Care Organization and Financing (ISHCOF). *Int J Health Care Finance Econ* 2007; 7: 73–111
26. Caskey FJ, Schober-Halstenberg HJ, Roderick PJ *et al.* Exploring the differences in epidemiology of treated ESRD between Germany and England and Wales. *Am J Kidney Dis* 2006; 47: 445–454
27. Slade EP, Anderson GF. The relationship between per capita income and diffusion of medical technologies. *Health Policy (Amsterdam, Netherlands)* 2001; 58: 1–14