

Review Article

Review article: Use of renal registry data for research, health-care planning and quality improvement: What can we learn from registry data in the Asia–Pacific region?

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SUMMARY: We review renal registry data from the Asia–Pacific region with an emphasis on their uses in health care and in dialysis care in particular. The review aims to demonstrate the information value of registry data. While renal registry provides a useful data resource for epidemiological research, there are severe methodological limitations in its application for analytical or therapeutic research. However, it is the use of renal registry data for public health and health-care management purposes that registry really comes into its own, and it is primarily for these that governments have invested in national patient and disease registries. We apply data from several renal registries in the Asia–Pacific region to illustrate its wide application for planning dialysis services, for evaluating dialysis practices and health outcomes, with a view to improving the quality of dialysis care. In the course of preparing the review, we have found that the quality and accessibility of renal registry data were highly variable across the region. Given the value of renal registry, every country in the Asia–Pacific region should establish one or should ensure that their current registries are better resourced and developed. Greater data sharing and collaboration among registries in the region could help advance the nephrology to serve our patients better.

KEY WORDS: database, dialysis, economics, end-stage renal disease, epidemiology, registries.

We review health databases in general and renal registry in particular, with emphasis on its uses for a variety of purposes. We illustrate our discussion using relevant data from registries in the Asia–Pacific region.^{1–8} We hope that this will provide additional impetus for the further development of registries in this region; many of these registries remain underdeveloped and their data or reports inaccessible. We further hope that in time to come there will be greater data sharing among these registries to enable collaborative research, including that on many of the issues raised in this review.

WHAT IS A HEALTH DATABASE, PATIENT AND DISEASE REGISTER?

A health database is any systematic compilation of data for the purpose of health care planning, implementation and

evaluation in a defined population. The data compiled are periodically published as statistical information to describe and analyze the state of the health of the population. Health databases come in a variety of guises, varying by their target entities, population coverage, type of data collected and their principal uses. Two general types are distinguished:

- 1 Patient registers are organized systems that use observational study methods to collect uniform data (clinical and others) to evaluate specified outcomes for a population defined by a particular disease or therapy (target disease or therapy), and that serve one or more predetermined scientific, clinical or policy purposes.^{9,10} Examples of these are the Australian/New Zealand and Malaysian renal registries.^{9,10}
- 2 Disease registers are continuous, systematic collections of data on all cases of a disease occurring in a defined population with the purpose of assessing and controlling the impact of the disease in the community.^{11,12} Examples are the various national cancer registries.¹¹ Disease registers are closely related to public health or disease surveillance¹³ though disease registers compile individual case level data while disease surveillances obtain data on the target disease from a variety of sources in addition to individual cases.

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Table 1 Patient registers and disease registers compared

No.	Characteristics	Patient registers	Disease registers or surveillance
1	Cases	Often focused on disease treatment.	Focused on disease occurrence.
2	Source of cases	Participating clinical units.	Various and multiple.
3	Denominator	Not defined.	Well-defined population, often geographically.
4	Data	Diagnosis, prognostic characteristics, variety of outcome measures. 'Clinically rich'	Case descriptor, demographics, \pm outcome such as mortality. 'Basic data'
5	Principal uses	<ul style="list-style-type: none"> • Patient care and disease management. • Clinical audit and quality improvement. • Health outcomes assessment. • Health technology assessment. • Monitor safety of therapeutic products and services. • Clinical research. 	<ul style="list-style-type: none"> • Disease burden measure. • Disease descriptive epidemiology. • Disease aetiology or risk factors. • Needs assessment. • Public health surveillance. • Epidemiology research.
6	Advantages and disadvantages	Comprehensive, clinically rich data but not representative and cannot provide population estimates of disease or treatment rates. Approximates a disease register when access to treatment becomes near universal.	Representative of population and can therefore provide estimates of disease or treatment rates; but only basic data and completeness of case ascertainment may be uncertain.

Table 1 compares patient registers and disease registers/surveillances. They have many similar characteristics, and in health systems where there is universal access to treatment, a patient register with complete participation from all clinical units in a country would approximate a register of disease for which the treatment is intended. Hence, many national renal registers have characteristics of both patient and disease registers.

GENERAL PURPOSES OF PATIENT AND DISEASE REGISTERS

The operation of a register incurs considerable expenses which are often publicly funded. Hence, registers must continuously assure their relevance and justification^{14,15} and serve an information need that cannot be otherwise provided, such as the following.

Information needs for public health

- 1 Quantifying disease burden and its geographic distribution and temporal trend. For example, with universal access to treatment, the incidence of treated end-stage renal disease (ESRD) would approximate the incidence of ESRD in a country.
- 2 Public health surveillance to detect disease epidemics or provide early warning of rapid increase in disease incidence. For example, epidemic of hepatitis C virus (HCV) infection occurring in some haemodialysis (HD) units.
- 3 Identifying population subgroups most at risk of disease. For example, certain minority ethnic groups may be particularly susceptible to ESRD.
- 4 Monitoring impact of preventive or control measures. For example, successful implementation of effective

preventive measures ought to translate into declining ESRD incidence over time.

Information needs for health-care management

- 1 Planning the provision of health care requires tracking the level and distribution of services.
- 2 Health technology assessment, to quantify the health impact of new technology, such as a new drug or device.
- 3 Evaluation of health services, including clinical and cost-effectiveness evaluation of health-care intervention.
- 4 Health-care quality improvement (clinical audit), based on measures to reduce variation in performance among providers.

Information needs for monitoring the safety of therapeutic products and services

Active surveillance system for the occurrence of unexpected harmful events associated with a product and service in a population. This is superior to the current practice of spontaneous reporting by users of the product or service to manufacturers and health authorities. Regulatory authorities are increasingly favouring this use.¹⁶

Data for clinical research

- 1 Clinical research on disease presentation and prognosis, and treatment effectiveness (to contrast with treatment efficacy in clinical trial).

- 2 Epidemiology research such as studies on disease occurrence and distribution, disease risk or aetiology and disease prevention.
- 3 Health economic research to evaluate the cost-effectiveness of health-care intervention.

INFORMATION VALUE OF RENAL REGISTRY

In this section, we elaborate on the use of registries in the following areas, using data from regional registries to illustrate our discussion: (i) renal registry data for research; (ii) dialysis service planning and dialysis economics; (iii) health outcomes assessment and dialysis practices; and (iv) dialysis quality improvement (clinical audit).

Registry data for research

Although there are similarities between registries and research, it should be emphasized that they are not the same. Research is intended to produce generalizable knowledge, while the statistical information provided by a registry is meaningful only in its setting, there is no pretension that the reported findings are generalizable to other populations. For example, a national registry may report that the incidence of ESRD is 100/million population (pmp) in a country, or that it found large variations in prescribed Kt/V among dialysis practices there. These observations strictly pertain to that country though of course they are useful and may highlight important problems that need to be remedied elsewhere.

Registry data could also potentially be used to address a specific research question. In research design terms, a registry database research would be an observational cohort study. Such a design is particularly appropriate for epidemiological research.¹⁷ A recent example uses registry data to show the wide variation in incidence of ESRD among various ethnicities.¹⁸ We adapted the results as shown in Figure 1. For each age group and for both diabetic and non-

diabetic causes, Asians have higher rates of ESRD compared with European peoples, but lower rates than Canadian aboriginals and Pacific Islanders. Such comparative study provides useful clues to possible risk factors for ESRD.

Registry data may also be appropriate in research to determine the treatment or causal effect of an intervention or exposure. The usual standard against which research validity is judge is the randomized controlled trial (RCT), widely regarded as the 'gold standard' method to provide the most robust estimates of treatment effects. Under certain conditions, observational study, such as a registry-based study, may well be the preferred design because RCT may be infeasible or ethically unacceptable, such as in situations where: (i) the postulated effect of exposure is harmful and it is not ethical to randomize subjects (to exposure vs non-exposure); (ii) the postulated treatment or causal effect is small and therefore the sample size requirement to adequately power the study may not be feasible; (iii) the outcome of interest is uncommon or would require an unusually long follow up to observe; and (iv) given the costs of clinical trials, only interventions with a high probability of observing a treatment effect will be subjected to trial, and, typically, these interventions would be drugs or medical devices, for which there already exists a large amount of basic, pre-clinical (animal) and early clinical studies to justify the ethics and expense of embarking on clinical trials to confirm their treatment effects.

However, regardless of the potential advantages of registry-based research, one should always be cautious in interpreting its results. Potential pitfalls include:¹⁹⁻²¹

- 1 Selection of study population. In registry databases, exposure to factors of interest or a treatment are almost certainly non-random. Use of registry data to evaluate the effects of a therapy is especially problematic because intentional treatment selection is inevitable.
- 2 Selection of time period. Selection of the appropriate time period for inclusion in a study is important to minimize the effect of changes in underlying conditions such as changes in inputs (e.g. quality of staff, technology and access) or changes in practice patterns.
- 3 Adjustment for confounding factors. In registry-based studies, the observed treatment or causal effect must be adjusted for confounding factors, typically by multivariable regression or some other statistical methods. However, even adjusted estimates may be too simplistic for several reasons: (i) not all known confounders may be included because the required data was simply not collected by the registry; (ii) measurement of confounders may be imprecise or of insufficient detail; and (iii) there will always be unknown confounders (residual confounding), which is inevitable in all observational studies (clinical trial overcomes this problem by randomized allocation to treatment groups).

It should be emphasized that it is the use of registry for purposes other than research that registry really comes into its own. The rest of this review demonstrates the value of

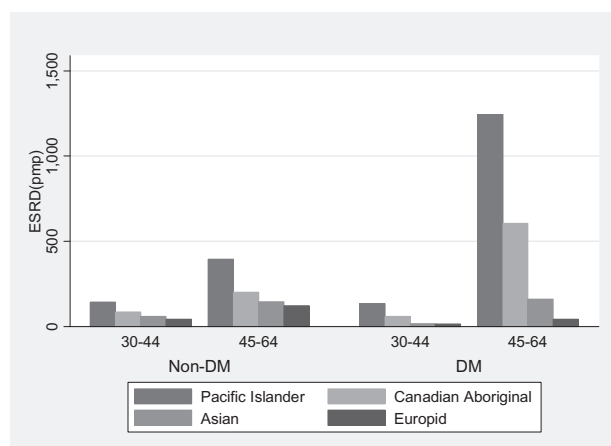


Fig. 1 Age- and sex-standardized incidence rates for all diabetic and all non-diabetic end-stage renal disease (ESRD) among various ethnic groups.¹⁸ pmp, per million people.

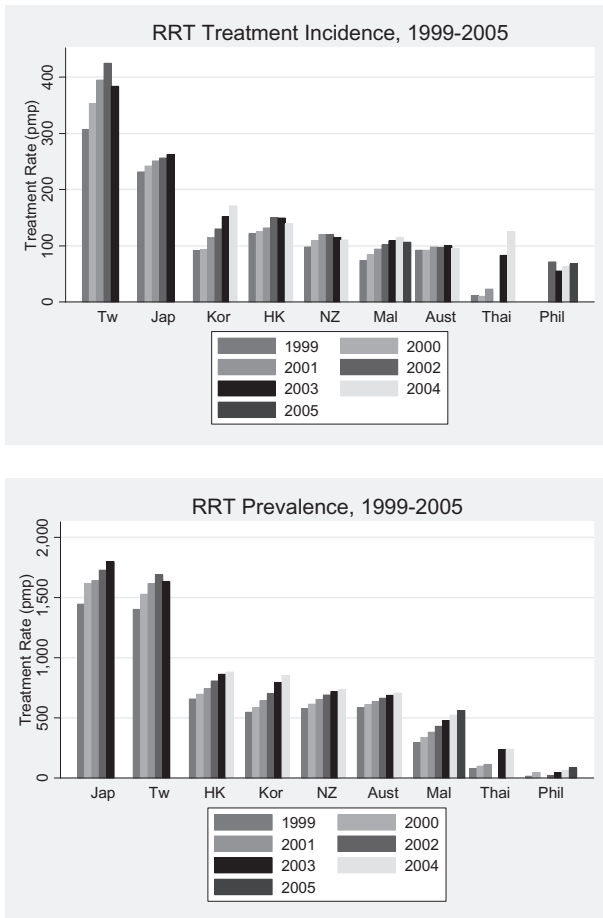


Fig. 2 Incidence and prevalence of renal replacement therapy (RRT) among various countries in the Asia-Pacific region. pmp, per million people.

such information, and it is primarily for these purposes that national registries are established.

Dialysis services and economics

One of the most important uses of national renal registry is to track the provision of dialysis services in a country. The level of provision fundamentally determines access to live-saving dialysis therapy in a population. Figure 2 shows such statistics from several countries in the Asia-Pacific region. All countries registered increasing levels of provision between 1999 and 2005 although there is marked variation among countries.

The variation in provision among countries seems most obviously related to level of national income. Figure 3 shows an obvious positive correlation between the level of renal replacement therapy (RRT) provision and per capita gross national product (GNP, a measure of national income) among countries,²² however, there remains variations unexplained by national incomes alone. Taiwan, for example, has a much higher treatment rate predicted by its income level

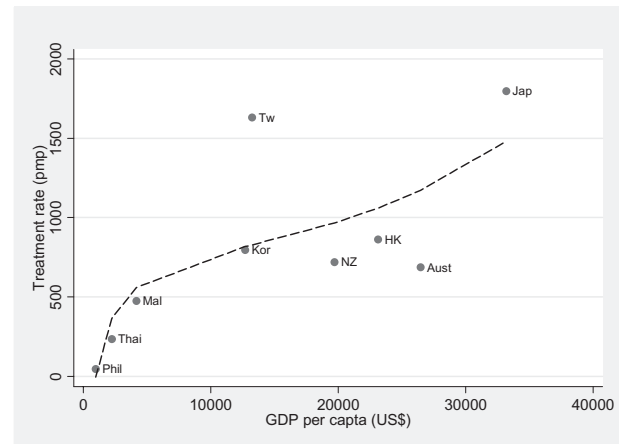


Fig. 3 Relation between level of renal replacement therapy (RRT) provision and per capita gross domestic product (GDP) or health-care expenditure among countries in the Asia-Pacific region in 2003. pmp, per million people.

while Australia is the opposite (Fig. 3). Other factors that may account for these variations in RRT apart from national income are: (i) differences in ESRD incidence (the graph plotted data on treated ESRD rather than incidence of ESRD); (ii) differences in acceptance for dialysis therapy (some countries accept everybody on dialysis including the very old with severe comorbidities, while others may be more selective); and (iii) differences in ascertaining patients on RRT (some countries count all dialysis, including acute or short-term hospital-based treatment while others only include those in a chronic dialysis program).

Besides comparing the levels of RRT provision among countries, it is no less revealing to examine the trend and distribution of RRT provision within country. Typically, one would be interested in: (i) changes in RRT provision over time; and (ii) significant, and perhaps unjustifiable, differences in provision among sociodemographic groups (e.g. are women, the elderly, the indigents or certain ethnic groups systematically being excluded from dialysis?) or among geographic regions in a country.

An example from the Malaysian renal registry¹ should illustrate this point. Figure 4 shows the change in dialysis incidence rates and GDP between 1980 and 2004. It is obvious that increase in RRT closely parallels economic growth. Such data can be persuasive, or even decisive, in policy making on resource allocation. Thus, if dialysis provision is not in keeping with rising income in a country, then a strong case can be made for increasing resource allocation for the dialysis sector. Such an economic interpretation of treated ESRD trend data would be appropriate for many of the low- and middle-income countries in Asia where access to dialysis is still problematic. Large increase in provision from initial low levels and over a relatively short period of time is certainly due mostly to increasing resource allocation for RRT, in parallel with economic growth. In contrast, interpretation of rising ESRD incidence in developed countries, such as Australia where universal access to

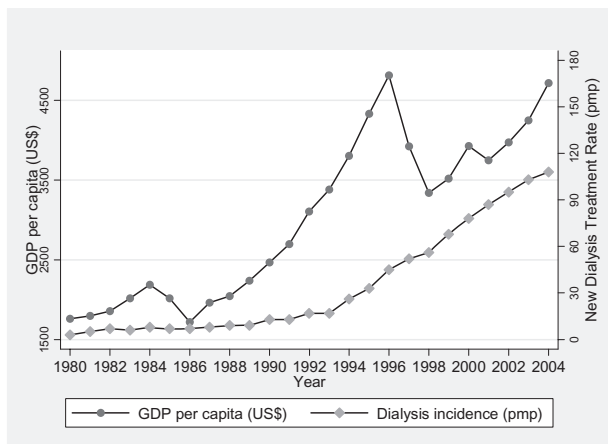


Fig. 4 Malaysian dialysis treatment rates and gross domestic product (GDP) per capita between 1980 and 2004. pmp, per million people.

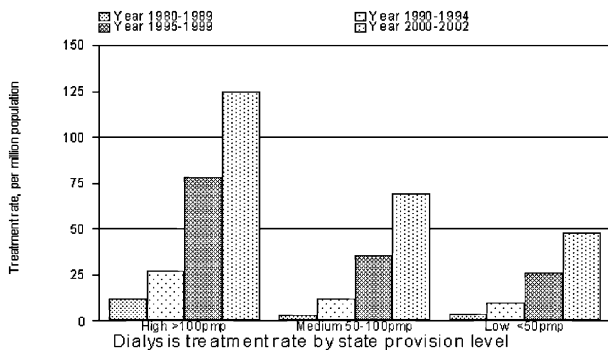


Fig. 5 Distribution of dialysis treatment among high-, medium- and low-provision regions in Malaysia between 1980 and 2002.

RRT is the norm, is fraught with difficulties. One must consider the effects of demographic changes, disease control measures, secular changes in practices (time to initiate RRT, attribution of primary renal disease) and competing risks.²³

Besides examining trends, the distribution of dialysis provision within country allows us to address health-care equity concern. Figure 5 shows dialysis treatment rates among the various states in Malaysia, divided into three regions (high-, medium- and low-provision regions) for the purpose of this analysis. Clearly, there are huge differences among the regions indicating perhaps that inhabitants of some parts of the country are being systematically denied access to dialysis. And worst of all, the figure also shows that the differences appear to persist over some two decades. The usual explanation for such differences is the economic disparity among the regions in a country, which has parallel in differences in RRT rates among countries (Fig. 3). A systematic way to examine inequity in distribution of health-care resources, such as dialysis, is to plot the so-called concentration curve.²⁴ Figure 6 plots the cumulative mean house-

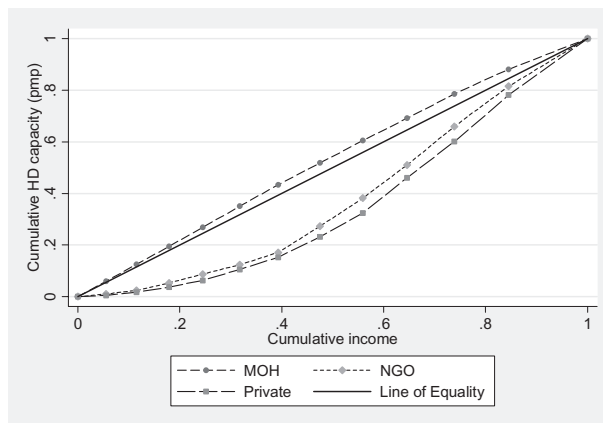


Fig. 6 Concentration curve for dialysis provision for the public (Ministry of Health, MOH), private and charity (non-governmental organizations, NGO) sectors in Malaysia. HD, haemodialysis; pmp, per million people.

hold income of the various states in Malaysia versus their cumulative HD treatment capacities for each of the provision sector separately. As is common in other Asian countries unable to provide universal access to dialysis, dialysis provision in Malaysia is divided among three sectors: (i) the public sector where treatment is entirely publicly funded; (ii) the private sector where patients or their employers pay for the treatment; and (iii) the charity sector that raises funds through public donation to provide dialysis for that section of the population unable to get into the public program or afford private dialysis. One would expect the private sector to concentrate its facilities in economically developed regions and the public sector to do exactly the opposite in accordance with its social equity mission, while the charity sector would be intermediate between the two. The dialysis provision concentration curves in Malaysia show exactly what was expected (Fig. 6). Overall, there is only a slight inequity in distribution of dialysis resources (if dialysis is equally distributed, the curve coincides with the diagonal; otherwise it lies beneath the diagonal, and the further from the diagonal, the greater the inequity in favour of the economically advantaged). Private provision follows where the purchasing power is (its curve is way below the line of equity), as one would expect for any other marketable goods and services, while the public sector, playing its complementary role to ensure health-care equity, clearly shows a pro-poor bias (its curve is above the line of equity). What is surprising perhaps is the economic behaviour of the charity sector to more closely resemble the private sector than the public sector. This could be because many providers in the charity sector could not raise sufficient funds and do accept fee-paying patients to cross-subsidize the indigent ones.

Health outcomes assessment and dialysis practices

Health-care funders, be they government, employer, insurance or charity organizations, are increasingly demanding

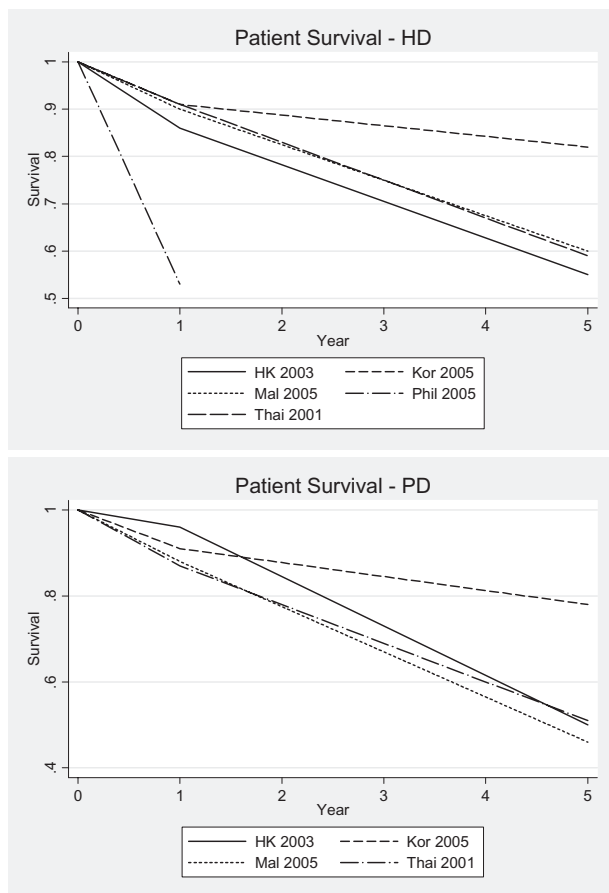


Fig. 7 One- and five-year patient survival on haemodialysis (HD) and peritoneal dialysis (PD) among several countries in the Asia-Pacific region.

'value for money'. One way to provide that assurance is to periodically publish data on how patients fare on dialysis. National renal registries, being neutral and independent bodies in most countries, have an important responsibility to systematically undertake such evaluation in an objective and anonymized fashion. Evidence of achievement of health outcomes comparable to results from other registries provides reassurance not only to payers, but also to our patients and our professional colleagues.

Figure 7 shows patient survival statistics from several countries in the Asia-Pacific region for HD and continuous ambulatory peritoneal dialysis. Most countries have quite comparable results at 1 year, but there are obvious differences in outcomes among countries at 5 years. For meaningful comparisons of mortality outcomes, one should adjust for obvious differences in patient profiles (e.g. countries with older patients with more comorbidities would have higher mortality rates) and differences in dialysis practices (e.g. resource inputs, dialysis technology, access to medicines). We do not have access to data to conduct such an adjustment in this review.

Nevertheless, one should be especially interested in differences in potentially modifiable factors that may underlie

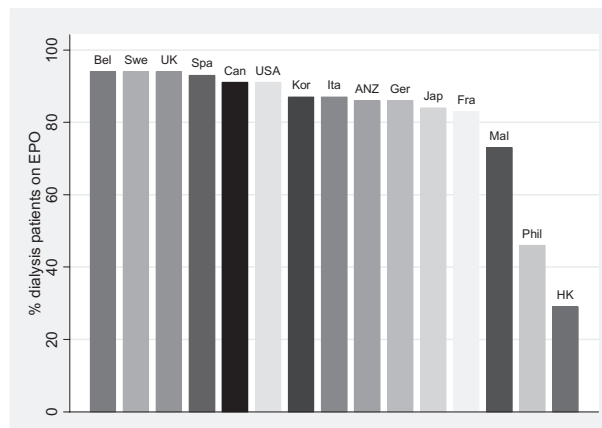


Fig. 8 Variation in epoetin utilization among several countries in the Asia-Pacific region and the 12 countries in the DOPPS study, 2002–2003 and 2004.²⁵ EPO, epoetin.

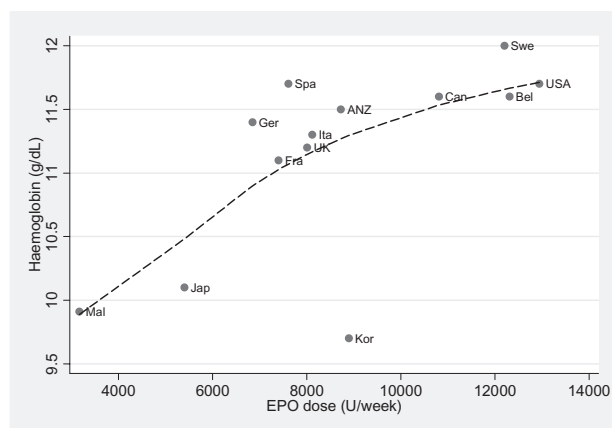


Fig. 9 Relationship between populations' epoetin (EPO) utilization and mean hemoglobin (Hb) levels. pmp, per million people.

the observed differences in mortality among countries. As an illustration, variation in epoetin utilization for example may be one factor. Figure 8 shows the relationship between epoetin utilization and hemoglobin (Hb) outcomes among several countries in the region, as well as for the 12 developed countries in the DOPPS study.²⁵ Asian countries in the sample are under-using epoetin, and this includes relatively wealthy Asian countries such as Japan. Notwithstanding other factors that may influence Hb outcome such as iron levels, it is clear that as a country's utilization of epoetin increases, more patients will be able to achieve the Hb therapeutic target (i.e. >11 g/dL), as shown in Figure 9 which demonstrates a clear positive relationship between the level of epoetin utilization and mean Hb levels achieved among populations. Variation in cost barrier to epoetin treatment is the most obvious explanation. In other words, there is a mismatch between available resources and the current prices of epoetin. To improve access to epoetin

treatment, either more resources have to be found or the price of epoetin has to reduce. With the advent of 'biogeneric' epoetin, the latter scenario looks increasingly possible. Indeed, biogeneric epoetins are already available in several Asian countries (such as Thailand, Philippines, Indonesia, China and Korea). It would be interesting to observe from their experiences whether the introduction of biogeneric epoetin leads to increasing epoetin use and improving Hb outcomes, as one would expect from experience with other generic medicines.

Dialysis quality improvement and clinical audit

No health-care system can provide all its clients with services that have flawless quality characteristics simply because there is an inevitable amount of variation in the performance of any service. Although performance variation is ubiquitous and it hurts patients, it cannot be eliminated but may be minimized. Quality improvement in health-care is essentially about how to reduce such variability in the processes and outcomes of patient care.

Variation in dialysis practices among providers is ubiquitous wherever effort is made to document it. Figure 10 shows one example from the Malaysian registry.¹ The huge variation in the proportion of patients with blood flow rates (Qb)

greater than 250 mL/min on HD among the more than 200 HD centres in Malaysia. Three centres have no patients with Qb of more than 250 mL/min, while a small number of centres have all their patients with Qb of more than 250 mL/min.

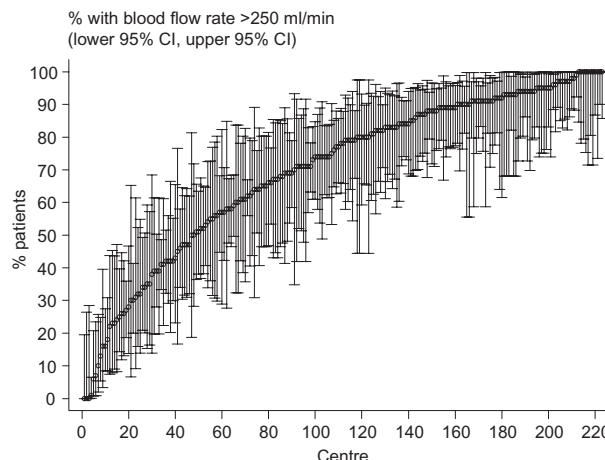
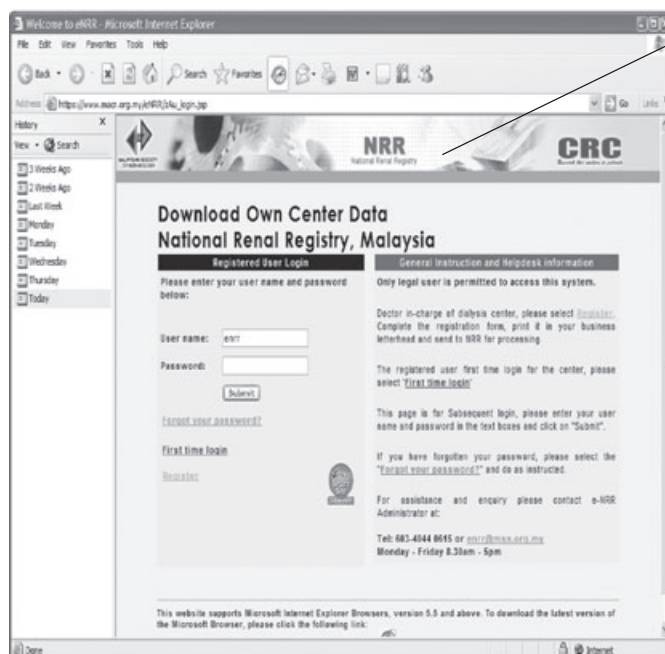


Fig. 10 Variation in proportion of patients with blood flow rates greater than 250 mL/min among haemodialysis (HD) centres in Malaysia.¹ CI, confidence interval; pmp, per million people.

Centre Report Card



**NATIONAL RENAL REGISTRY
CENTRE REPORT CARD 2005**

CENTRE:

Parameter of interest	5 th centile	Median	95 th centile	Your Centre
1. Anaemia Management				
EPO utilization (% pts)	55	83	100	88
Median serum ferritin on EPO	257	621.5	1024	479
Median TSAT on EPO	24.1	32.6	49.5	36.6
Median Hb on EPO	8.8	10	11.2	10.9
% with Hb > 11g/L	4	23.5	55	44
2. Nutritional status				
% with Sr albumin >40g/L	10	57	88	18
% with BMI ≥ 18.5	70	88	100	70
3. BP and Lipids				
Median systolic BP	137.2	150.6	161.8	151.0
Median diastolic BP	73.5	80.8	87.3	84.9
% with BP < 140/90 mmHg	10	27	57	28.0
Median sr cholesterol	4.2	4.6	5.2	4.8
Median sr triglycerides	1.3	1.7	2.2	1.5
% with sr cholesterol <5.3 mmol/L	55	73	90	76.0
4. Renal bone disease				
Median serum calcium	2	2.3	2.4	2.3
Median serum phosphate	1.4	1.8	2.1	1.7
Median calcium-phosphate product	3.2	3.9	4.8	4.0
% with serum phosphate <1.6 mmol/L	15	37	63	39.0
% with calcium phosphate product < 4.5	45	69	91	75.0
5. Hepatitis				
% with anti-HCV	0	9	40	0
% with HBsAg	0	1	14	0
6. HD practices				
Median blood flow rate	250	300	350	300
% with Qb > 250 ml/min	22	78	99	77
Median Kt/V	1.4	1.6	1.9	1.8
7. PD practices				
% with Kt/V ≥ 2.0 per week	-	-	-	-
Peritonitis rate	-	-	-	-
8. Patient Survival				
% survival at 1-year (adjusted to age and diabetes)	74	99	100	90
% survival at 5-year (adjusted to age and diabetes)	25	73.5	100	50

Fig. 11 Centre Report Card issued by the Malaysian National Renal Registry.¹

The use of renal registry data to systematically document variation in performance among dialysis providers was first pioneered by the UK Renal Registry.²⁶ The Malaysian registry has adopted a similar approach, and took the next obvious step to provide individual dialysis centres their own so-called 'Centre Report Card'. The report card, as its name indicates, simply lists results achieved by a centre for the various agreed performance indicators and compares the results against the national fifth percentile, median and 95th percentile results. The results are released in strictest confidence to each centre participating in the program through a highly secured website as shown in Figure 11. The objective of such feedback is implicitly to change providers' behaviour to improve clinical and service performance. Recent reports from the registry¹ indicate that by using such simple feedback alone, one could drive improvement in performance of such indicators like blood pressure control, Kt/V prescribed and Qb, which are entirely within the control of providers, while having less success in others. Whether such improvements will lead to better patient health outcomes remains to be seen.

CONCLUSION

We have reviewed renal registry data from the Asia-Pacific region to illustrate its many uses for dialysis service planning, health-outcome assessment and quality improvement. This demonstrates that renal registries do serve a need for information that could not otherwise be met. Every country in the region should have its own registry or should ensure their registries are better resourced and developed. Greater data sharing among registries in the region could help advance nephrology to serve our patients better.

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