

# Renal registry in Hong Kong—the first 20 years

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Renal Registry was started by the Hospital Authority (HA) in Hong Kong in 1995. It is an online system developed by HA. It collects all patients under care in HA, which is about 90–95 % of all requiring renal replacement therapy (RRT) in Hong Kong. The total number of patients treated increased from 3312 in 1996 to 8510 in 2013. In 2013, there were 3501 renal transplant, 1192 hemodialysis (HD) and 3817 peritoneal dialysis (PD) patients. In 2013, 1147 new patients joined the RRT program, 49.6% of them suffered from diabetic nephropathy. Glomerulonephritis and hypertension are the 2nd and 3rd most common causes of RRT in Hong Kong. The median age was 59.1 years with male to female ratio of 1.54 to 1. Hong Kong practices 'PD first' policy and the majority of the patients are on CAPD treatment. The ratio of PD to HD was 76.2% to 23.8%. Eighty-six percent of all PD patients are on CAPD; the remaining 14% are on automated peritoneal dialysis (APD). Sixty-five percent of all dialysis patients are on erythropoiesis-stimulating agent treatment. The Hong Kong Renal Registry with online real-time data input and access can provide timely data and information to facilitate patient care and management and also provides invaluable data to help in development and planning of renal services in Hong Kong.

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## RENAL SERVICES IN HONG KONG

Hospital Authority (HA) provides the renal replacement therapy (RRT) and care of over 90% of end-stage renal failure in Hong Kong. There are 15 renal units under seven HA clusters in providing RRT. There are four renal transplant centres in Hong Kong (HK)—Princess Margaret Hospital, Prince of Wales Hospital, Queen Elizabeth Hospital, and Queen Mary Hospital.

## HONG KONG RENAL REGISTRY SYSTEM

The Renal Registry is a direct, online, computerized registry system developed by the Central Renal Committee, Hospital Authority (HA), to capture data of all public RRT patients in Hong Kong under HA. It was first implemented in 1995 with special renal registry terminals in Renal Units for data entry and retrieval, connecting through WLAN, to a central server. It is a self-developed program and database and data are entered directly online by all renal units. Currently, all eligible users (renal unit staff) can access the Renal Registry System not only from designated Renal Registry Terminals, but all Clinical Management System Terminals, which is linked to the same information superhighway (WLAN) using a preset link to call up the function from the HAHO designated server. Each individual renal unit can access their own patient data online, as to facilitate both individual patient management and provide important and valuable data for the unit as a whole. HA Head Office can produce up-to-date registry data for the whole HA; the data are important for audit, monitoring and planning of future services. Renal Registry is part of the Organ Registry and Transplant System, which has a component of other organ registries, Organ Procurement System and Transplant and Immunogenetics System. Organ Procurement System is used by the transplant coordinators for cadaveric donors. Potential donor demographics, clinical conditions, immunological and virology results are stored. Transplant and Immunogenetics System is used by the designated Transplant and Immunogenetics laboratory to centralize the transplantation immunogenetics and tissue typing services. An important function of the Renal Registry is to serve the central Cadaveric Kidney Allocation. A scoring system based on the years on RRT, the HLA matching and the age of patients is developed to determine the priority of the potential recipient list. The donor clinical information including virology results can be obtained directly online. The direct communication, data exchanges and downloading

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among the different systems avoids unnecessary data transcription and hence minimize the error.

Currently, there is a Renal Registry Steering Group and an Implementation Team formed under Central Renal Committee, HA to look after the direction and development together with the daily running and wellbeing of the system and data, respectively.

**MILESTONES OF RRT IN HONG KONG**

The first acute hemodialysis (HD) was started in Hong Kong in 1962 (Figure 1). This was followed by chronic maintenance HD. The first cadaveric kidney transplant was performed in 1969 and the first living-related renal transplant in 1980. In 1980s, continuous ambulatory peritoneal dialysis (CAPD) was introduced. In 1985, the PD-first policy was adopted in HA. Automated PD was started in 1989. Despite the PD-first policy, there was also gradually a growing need for HD support for those PD patients who needed to switch because of complications and inadequate dialysis of PD. Nocturnal home HD was introduced in 2006, and a public-private partnership HD program was introduced since 2010. The data collected through RR have an important part in planning of renal services of Hong Kong.

**INCIDENCE AND PREVALENCE**

In 1996, the number of incident patients was 615. In 2013, the number was steadily increased to 1147, making the incidence rate to 159 per million population (Figure 2). In 1996, there were 3312 patient on RRT (956 transplant, 491 HD, and 1865 PD). The number increased steadily and by 2013, there were 8510 RRT patients (3501 transplant, 1192 HD, and 3817 PD) (Figure 3).

**DEMOGRAPHIC DATA**

For the year ending 31 December 2013, the median age of prevalent patients receiving RRT was 51.4 years, 44.6% of them were over 60 years and 18% were over 70 years. For new patients entering into RRT program in 2013, the median age was 59.1 years, 47.6% were over 60 and 22.1% were over 70 years. The trend of increasing number of elderlies in and entering into the RRT program was observed. Figure 4 shows

the rising age of incident patients put on PD with a significant rising trend in the age groups of 45–64 years and older than 75 years.

**GENDER**

The male to female ratio of prevalent patients showed a gradual increase from 1.09 in 1996 to 1.29 in 2013. The incident patient also showed a similar trend from 1.28 in 1996 with further increase in male preponderance to 1.54 in 2013.

**PRIMARY RENAL DISEASE**

Twenty-nine percent of new patients entering RRT in 1995 was due to glomerulonephritis, which showed a steady decrease to 17% in 2013. However, that from diabetes mellitus increased from 26.2% in 1996 to 49.6% in 2013. Figure 5 shows the trend of absolute number of the causes of new cases of RRT from the year 1996 to 2013.

**RENAL REPLACEMENT THERAPY**

Of the 1147 new patients in 2013, 953 are on PD, 159 on HD, and 158 on renal transplant. More than 86% of new patients requiring dialysis are put on PD. In 2013, there were 1991 renal failure patients waiting for a kidney transplant. That year, 69 Cadaveric and 12 living-related transplantations were performed in HK, whereas 77 were performed outside HK. Thirty-five renal transplants were performed without any prior dialysis therapy (3%).

In 2013, 3817 of prevalent patients were on PD, 1192 HD, and 3501 had transplant. The ratio of PD:HD was 76.2:23.8. Eighty-six percent of PD patients are on CAPD and the remaining 14% are on APD. There was a gradual trend of increasing use of APD (Figure 6). In all, 90.5% of HD is provided by in-patient centres. The prevalent kidney transplant patients showed a steady rise from 1996 till 2013 with increase mainly in the area of deceased donor renal transplantation (DDRT), whereas live donor renal transplantation patient numbers were relatively stable for the past 10 years (Figure 7).

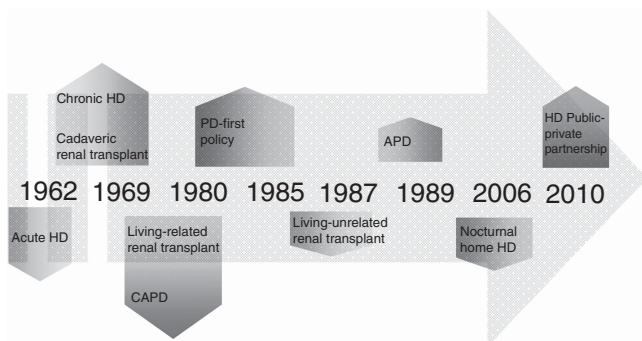
**ERYTHROPOIESIS-STIMULATING AGENTS**

In 2013, there were 65% of all RRT patients receiving erythropoiesis-stimulating agents (Figure 8). It was 29.3% in 1996. This was as a result of a significant increase of funding from the Government in the recent years to enhance the treatment of renal anemia in our RRT patients.

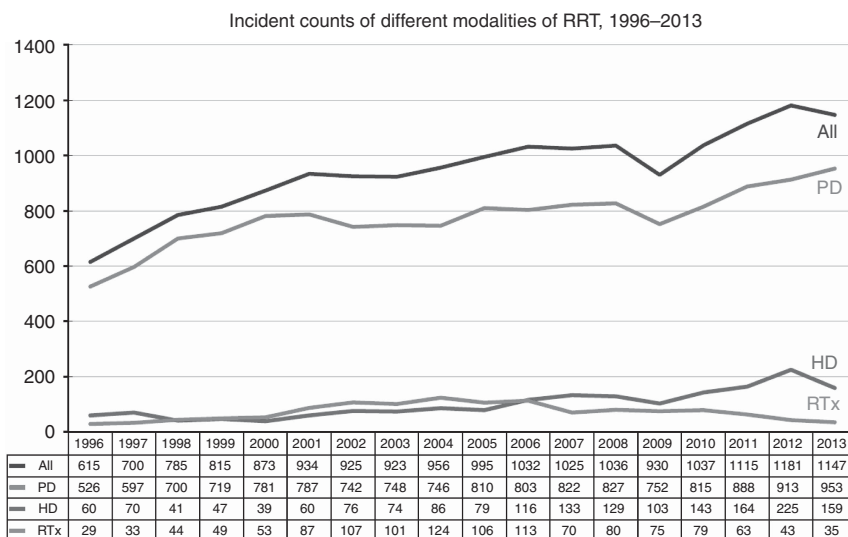
**DISCUSSION**

The number of patients suffering from chronic kidney disease (CKD) is ever increasing. Early detection and management of renal disease is important to reduce the burden of end-stage renal failure requiring RRT. HA started the development of renal registry to help centres in collecting data systematically through daily patient management. The system was custom built for and by the clinicians with good input of data.

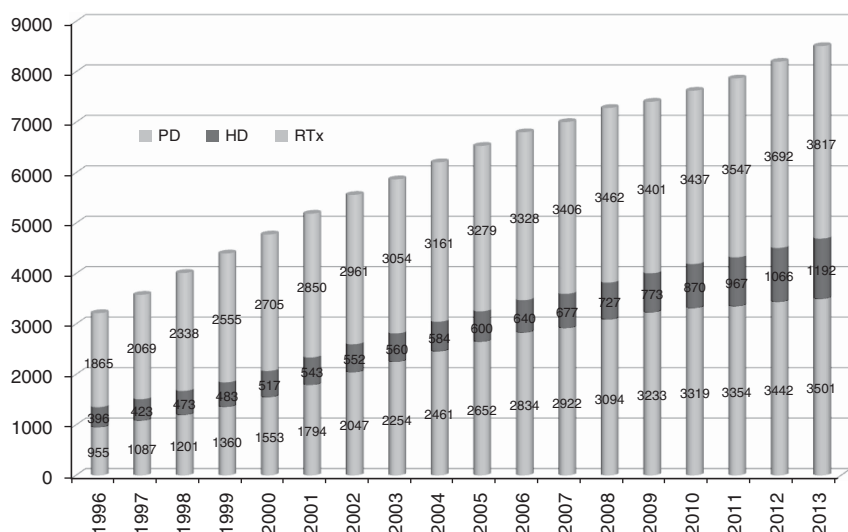
Hong Kong, like many parts of the world, is seeing a gradual but significant increase in prevalent cases on RRT The



**Figure 1 | Milestones of renal replacement therapy in Hong Kong.** APD, automated peritoneal dialysis; CAPD, continuous ambulatory peritoneal dialysis; HD, hemodialysis; PD, peritoneal dialysis.



**Figure 2 | Incident cases of renal replacement therapy (RRT) in Hong Kong, 1996–2013.** HD, hemodialysis; PD, peritoneal dialysis; RTx, renal transplant.



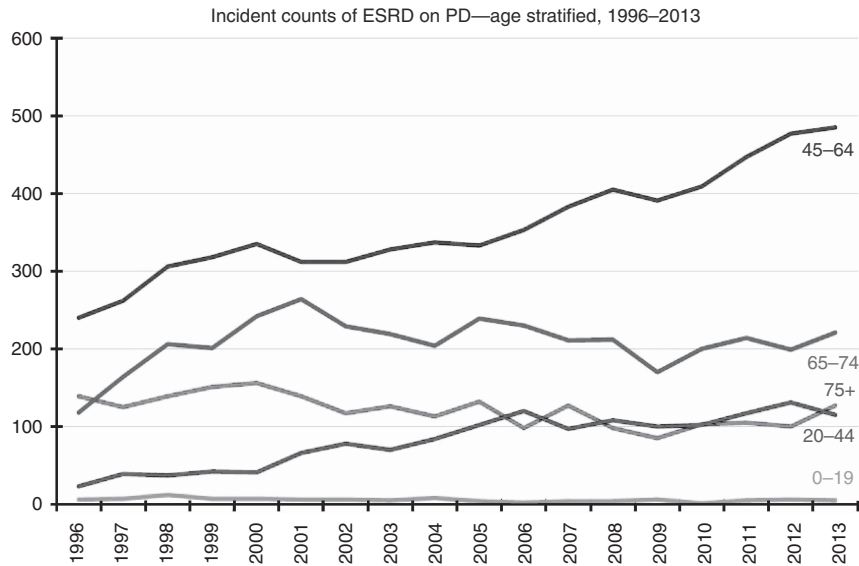
**Figure 3 | Prevalent cases of renal replacement therapy in Hong Kong, 1996–2013.** HD, hemodialysis; PD, peritoneal dialysis; RTx, renal transplant.

median age of prevalent patient on RRT is also shown to be increasing, and the biggest increase is seen in the age groups of 45–64 and over 75 years. RRT poses a heavy financial burden on the health-care systems around the world. The PD-first policy of Hong Kong was proven to be successful. It has been shown that no significant difference was found between PD and HD in patient survival around the world and it in fact may favor a slightly lower mortality in PD.<sup>1</sup> In Hong Kong, strategies to improve the longevity of PD had been adopted including the introduction of automated PD usage since 1997 (the number of patient using APD is more than 500 (13.9% of all PD treatment) in 2013), early use of Icodextrin for patient with ultrafiltration failure, and poor DM control. Overall, cost for home therapies and in

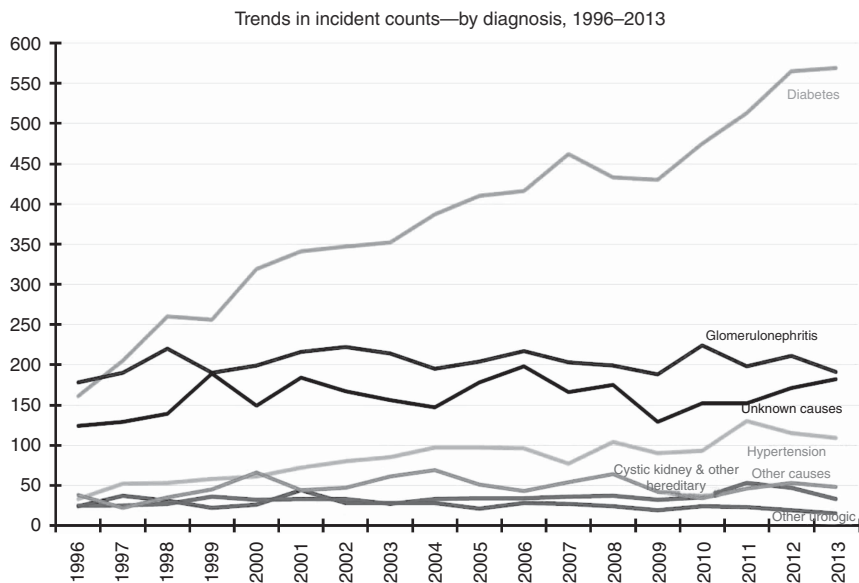
particular home PD is less expensive than in centre dialysis programs around the world.<sup>2</sup>

As a consequence, the percentage of PD to HD in Hong Kong was as high as 82% in 2008. At the same time, we do see the need for some of the PD patients who may benefit from a timely switch to HD. Various strategies such as expanding incentre HD service in HA, developing public–private partnership HD centres, and promoting home HD were started. The latest PD to HD percentage distribution has decreased to 76.2% and 23.8%, respectively, in 2013. Palliative care as an option for some CKD stage-5 patients is developed through good individualized therapy and treatment plan.

Erythropoiesis-stimulating agents were introduced for renal anemia, starting with self-payment in 1980s, then



**Figure 4 | Age trends of incident peritoneal dialysis (PD) population from 1996 to 2013.** ESRD, end stage renal disease.



**Figure 5 | Causes of incident new cases on renal replacement therapy, 1996–2013.**

subsidized programs, and finally through hospital provision. Patient general health and wellbeing were improved. The incidence of frequent blood transfusion with consequent side effects of iron overload was reduced. The incidence of hepatitis B and hepatitis C in dialysis population is also noted to be decreased.<sup>3</sup>

Transplantation is the best available RRT for those suitable patients.<sup>4</sup> Owing to the shortage of organ availability, in 2013, there were only 69 cadaveric renal transplants and 12 live donor renal transplantations done in HK.

The burden of increase demand on RRT from CKD affects Hong Kong as much as the global burden. This can only be improved with early detection of the CKDs by nephrologists

with the help from family physicians, general physicians and other health-care professionals, and patients themselves,<sup>5</sup> and also prevention of patients from suffering of acute kidney injury.<sup>6</sup>

There is a plan to automatic integration of information available in the HA Clinical Management System including the laboratory, pharmacy data into the system to avoid unnecessary transcription, and to facilitate the individual units to have their own data analysis and audit.

The data generated can be used to benchmark with International figures. The Hong Kong renal registry data were incorporated into United States Renal Data System (USRDS) annual report since 2000. This can help to improve the service

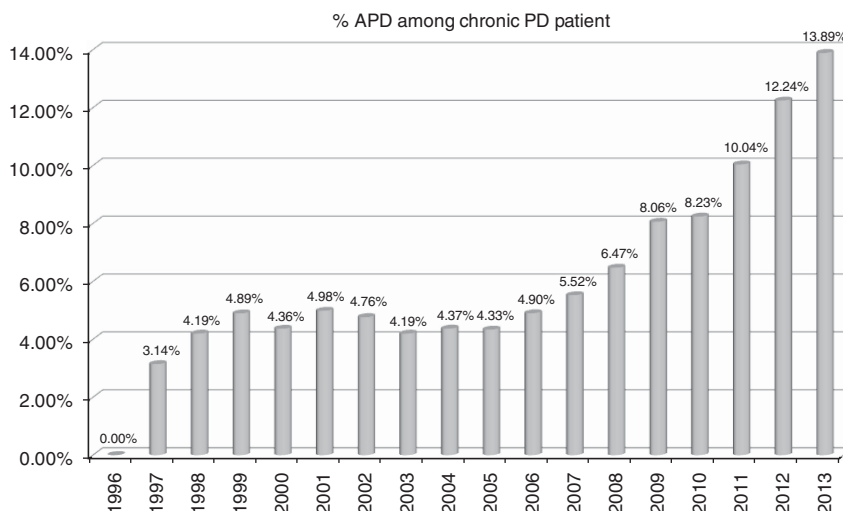


Figure 6 | Rising trend of utilization of automated peritoneal dialysis (APD). PD, peritoneal dialysis.

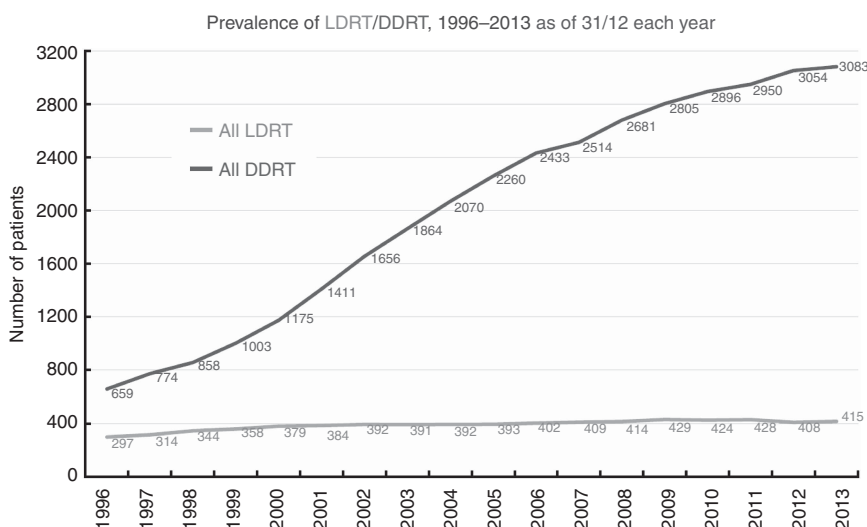


Figure 7 | Number of kidney transplant patients in Hong Kong, 1996–2013. DDRT, deceased donor renal transplantation; LDRT, live donor renal transplantation.

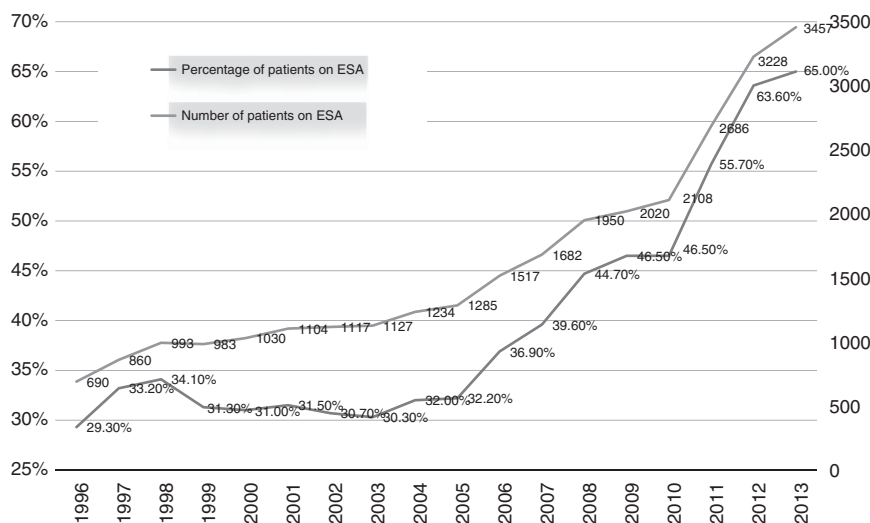


Figure 8 | Number and percentage of prevalent dialysis patients on erythropoiesis-stimulating agents (ESAs), 1996–2013.

in Hong Kong by a comparison with the rest of the world and also contribute toward a better understanding of epidemiology of renal failure among various ethnic groups and socioeconomic status.

### CONCLUSIONS

Renal Registry in Hong Kong is a computerized system that uses online real-time data input and access to provide timely data and information to facilitate patient care and management. It also provides invaluable data to help in development and planning of service and for projection of demand of renal services. The success of a registry requires the engagement of front-line staff in timely and accurate entry of the information, which in turn helps their own clinical work and management.

### DISCLOSURE

The authors declared no competing interests.

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