

**11TH REPORT OF
THE MALAYSIAN
DIALYSIS & TRANSPLANT REGISTRY
2003**

*Review of Dialysis Provision 1980 to 2003
Survey of Dialysis Practices 1993-2002
Analysis of RRT Outcomes 1997 - 2002*

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The Dialysis Association of
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FOREWORD

This special 11th Report reviews the progress made and looks at the trends in renal replacement therapy (RRT) over the years from 1980 to 2003, dialysis practices from 1993 to 2002 and analysis of RRT outcomes from 1997 to 2002. It has been a remarkable two decades. Starting from near the bottom of the league table of renal replacement program we have now moved to a more respectable position. While a lot more needs to be done, the achievements to date have been considerable. Everyone involved in the provision and management of RRT can be justifiably proud of the progress made. The National Renal Registry started with modest aspirations and even less resources. It has now consolidated its management, acquired new resources especially in IT and has reached out to all providers of RRT. Its single most important achievement in this period under review has been to garner the trust and cooperation of all providers who willingly submitted data regularly. Its management approach of keeping in regular contact with the providers, being responsive to their needs, meeting all deadlines goes a long way in ensuring success. Two key individuals, Dr Lim Teck Onn and Ms Lee Day Guat, played key roles in the success of the National Renal Registry thus far. Their drive, enthusiasm, management skills, obsessive attention to details are the critical success factors of the registry.

The number of new patients taken in for dialysis increased by more than 6.5 times over the last 10 year period. A truism shown in all countries is consistently seen in this report i.e. you can only treat that many you can afford. As the country's Gross domestic product increases so does the number of new patients taken in for dialysis. However for a country with an income and status of a developing nation, we see a pattern in our dialysis patients that is more commonly seen in the rich industrialized countries. Nearly half of the new patients taken in for dialysis were diabetics and the dialysis acceptance rates were highest amongst the older age groups. In these groups the acceptance rates continue to increase sharply.

A number of interesting features are seen in this report. The survival of dialysis patients in recent cohorts is lower than the earlier ones. Whether this is a reflection of the rapid proliferation of dialysis centers in recent years with the attendant problems of lack of experienced staff and supervising nephrologists is left to be seen in more detailed studies. Nonetheless it is a cause for concern. An economic evaluation of the cost of dialysis was included in this report. This was a study done on the Ministry of Health's dialysis program. The cost per life year saved on haemodialysis was quite similar to that for CAPD. This has important implications for the planning of future RRT program. For this 10 year review expert panels were formed to look into selected clinical areas in greater detail than the usual annual reports. While most of the findings are in keeping with reports in the literature and other registry publications, there are a few that warrants further study as they showed differing trends.

It would appear that taking in more patients for treatment will not pose a major hurdle given the trend seen in the last ten years and provided the country's economy continue to grow. A major challenge now confronts all RRT providers; where do we go from here and how can we build on this success. We now have to focus more on improving outcomes through improvements in the quality of treatment that we provide. The NRR can play an important role in this respect. Given the network it has established, the database it accumulated and the goodwill it has generated it would not be too difficult a task for the NRR to take on this new responsibility of promoting quality initiatives through regular monitoring and analysis of outcomes.

DR ZAKI MORAD
Chairman,
National Renal Registry.

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The members of the various panels for their expertise and of course for devoting their valuable time and effort in preparing and writing the various chapters.

Director of the National Registration Department (Jabatan Pendaftaran Negara), for allowing us to verify the status of those patient lost to follow-up.

And of course not forgetting our supporters from the industry and other well-wishers:

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Baxter Healthcare (Asia)

Gambro

MX Services

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And all others who have in one way or another contributed towards the success and the publication of this report.

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- 242 The Nayang-NKF Dialysis Centre
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- 254 Yayasan Hemodialisis Kebajikan Southern Melaka
- 255 Yayasan Kebajikan SSL Heamodialisis

ABOUT THE NATIONAL RENAL REGISTRY

The National Renal Registry (NRR) collects information about patients on renal replacement therapy (RRT) in Malaysia. This information is needed for the estimation of treatment rates in the country, as well as to assist the Ministry of Health (MOH), Non-Governmental Organization, private providers and industry in the planning and evaluation of RRT services.

The National Renal Registry (NRR) has its origin in the Dialysis and Transplant Registry established by the Department of Nephrology in 1992 to collect data from patients on renal replacement therapy within the MOH. In order to expand coverage to include all patients on RRT in the country so that the registry may truly claim to be a national one, the Malaysian Society of Nephrology (MSN) was invited to co-sponsor the registry in 1995. In 2001, the Clinical Research Centre of the MOH was designated as NRR collaborating unit to provide clinical operational, biostatistical and data management capabilities to support the operations of the NRR. The Dialysis Association of Medical Assistant and Nurses (DAMAN), a key professional counterpart to MSN, also agrees to co-own the NRR in 2002.

The objectives of NRR are to:

1. Determine the frequency and distribution of dialysis and transplantation in Malaysia. These are useful measures of the health burden arising of end stage renal failure and its treatment provision in the country
2. Determine the outcomes, and factors influencing outcomes of dialysis and renal transplantation. This serves the needs of outcome assessment.
3. Evaluate RRT program. This serves the need of accountability.
4. Stimulate and facilitate research on RRT and ESRD.
5. Maintain the national renal transplant waiting list.

The NRR receives data on RRT from 2 main sources:

1. The National Vital Registration system (Jabatan Pendaftaran Negara). These data are useful for determining or verifying mortality outcomes of patients on RRT.
2. The most important data sources are the individual doctors, medical assistants and nurses who care for patients on RRT, and voluntarily report data to the NRR.

NRR SPONSORS

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Dialysis Association of Medical Assistant and Nurses

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EXPERT PANEL

For each chapter of this report, the NRR established an expert panel comprising nephrologists and allied health professionals where relevant with expert knowledge in the area concerned.

The tasks of the Expert Panel were:

1. To undertake Quality Control of the reported data
2. To undertake literature review in the area relevant to the panel
3. To interpret the results presented in the NRR report
4. To write the chapter of the report relevant to the panel's expertise

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CLINICAL RESEARCH CENTRE

The Clinical Research Centre (CRC) is the designated collaborating unit to the NRR. It provides the functional capacity to support the operations of the NRR.

The CRC is the clinical research arm of the Ministry of Health. Apart from the NRR, CRC currently also supports the National Cancer Registry, National Cataract Surgery Registry, National Neonatal Registry, National Mental Health Registry, National HIV/AIDS Treatment Registry and National Transplant Registry.

In recent years, CRC has emerged to become the preferred collaborating partner for medical professional groups to establish disease and treatment registers in the country. This is because CRC possesses sophisticated facility and equipment, state of the art technology, and most importantly the trained human resources such as registry managers, clinical epidemiologists, biostatisticians, information technology professionals and other supporting staff skilled in registry operations. These resources are consolidated in the Disease and Treatment Registry Unit in the CRC. This unit specializes in assisting medical professionals to establish and operate their registries.

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