

August 2005
© National Renal Registry, Malaysia

Published by:

The National Renal Registry

2nd Floor, MMA House

124, Jalan Pahang

50286 Kuala Lumpur

Malaysia

Tel. : (603) 4045 8636

Fax : (603) 4042 7694

e-mail : nrr@msn.org.my

Web site: <http://www.msn.org.my/nrr>

This report is copyrighted. However it may be freely reproduced without the permission of the National Renal Registry. Acknowledgment would be appreciated. Suggested citation is: YN Lim, TO Lim (Eds). Twelfth Report of the Malaysian Dialysis and Transplant Registry 2004. Kuala Lumpur 2005

This report is also published electronically on the website of the National Renal Registry at: <http://www.msn.org.my/nrr>

Funding:

The National Renal Registry is funded with grants from:

Malaysian Society of Nephrology

The Ministry of Health Malaysia

Baxter Healthcare Asia

Fresenius Medical Care

Roche Malaysia

Cormed

ACKNOWLEDGEMENTS

The National Renal Registry would once again like to thank the following:

All the nephrologists, physicians and staff of the dialysis and transplant centres for their continued participation and hard work

Staff of the Clinical Research Centre, in particular Ms Teh Poh Geok for most of the statistical analysis and Azizah Alimat for the layout and formatting of this report

The Ministry of Health, Malaysia

Our Industry sponsors: Baxter Healthcare (Asia), Fresenius Medical Care and Roche for their generous support

&

All who have in one way or another supported and/or contributed to the success of the NRR and this report.

Dr. Zaki Morad
Chairman
National Renal Registry
Malaysia Society of Nephrology

NRR Advisory Committee Members

2004 to 2006

CHAIRMAN:	Dr. Zaki Morad B Mohd Zaher
MEMBERS:	Dr. Lim Teck Onn
	Dr. Lim Yam Ngo
	Dr. T. Thiruventhiran
	Dr. Tan Hee Wu
	Dr. Wong Hin Seng
	Mr. Tam Chong Chiang
	Ms. Norlida Omar
Secretariat	Ms. Lee Day Guat

NRR Office Staff

Clinical Registry Manager	Ms. Lee Day Guat
Clinical Research Assistants	Ms. Mardhiah Arifin Ms. Nor Azliana Ramli

CRC Technical Support Staff

Director	Dr. Zaki Morad B Mohd Zaher
Head	Dr. Lim Teck Onn
Epidemiologist	Dr. Jamaiyah Haniff Dr. Anita Das
IT Manager	Ms. Celine Tsai Pao Chien
Database Administrator	Ms. Lim Jie Ying Mr. Sebastian Thoo
Network Administrator	Kevin Ng Hong Heng Mr. Adlan Ab Rahman
Desktop Publisher	Ms. Azizah Alimat
Statistician	Ms. Teh Poh Geok
Webmaster	Mr. Patrick Lum See Kai
Desktop Publisher	Ms. Azizah Alimat

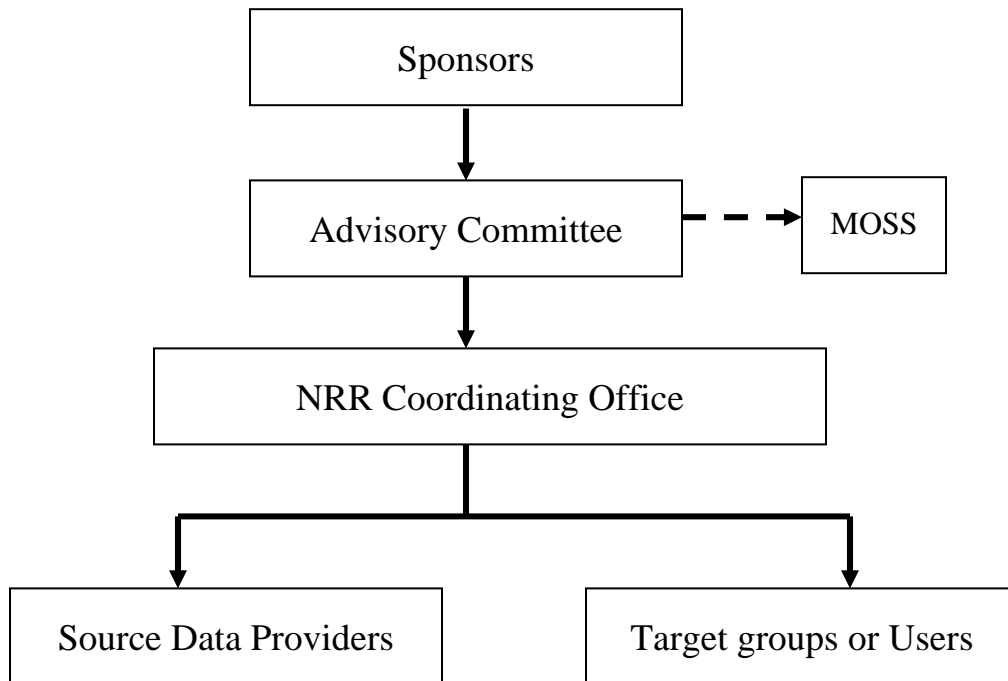
About the National Renal Registry.....

The National Renal Registry (NRR) has its origin in the Dialysis and Transplant Registry established by the Department of Nephrology in 1992. The sponsors of NRR are the Malaysian Society of Nephrology (MSN) and Association of Dialysis Medical Assistants and Nurses (ADMAN).

The objectives of NRR are to:

1. Determine the disease burden attributable to End Stage Renal Disease (ESRD), and its geographic and temporal trends in Malaysia.
2. Determine the outcomes, and factors influencing outcomes of Renal Replacement Therapy.
3. Evaluate the RRT program.
4. Stimulate and facilitate research on RRT and ESRD.
5. Maintain the national renal transplant waiting list.

The NRR organization is as follows:



Sponsors.

The Malaysian Society of Nephrology is the main sponsor of the National Renal Registry (NRR) and Malaysian Organ Sharing System (MOSS) and the co-sponsor is the Association of Dialysis Medical Assistants and Nurses.

Advisory Committee.

This is the committee established by the sponsors to oversee the operations of the registry.

National Renal Registry Office

The NRR office is the coordinating center that collects and analyses the data. It publishes the annual report of Malaysian Dialysis & Transplant Registry and the Directory of Dialysis Centres in Malaysia. The Clinical Registry Manager (CRM) oversees the daily operation of the NRR. The Clinical Research Centre of Hospital Kuala Lumpur provides the epidemiology, statistic and information technology support to NRR.

Source Data Producers

These are the dialysis centres that collect the required data. It is the most critical and yet difficult element of the system. It has to be systematic and uniform, and producers of source data need to be trained and motivated to ensure high data quality.

Users or Target groups

These are the individuals or institutions to whom the regular registry reports are addressed. It is their needs for information to assist in the planning and implementing disease treatment, control and prevention activity that justify the investment in the registry. They include:

1. the Renal community
2. the RRT provider
3. the Public health practitioner
4. the Decision maker in various government and non-government agencies who have responsibilities for any aspects of ESRD treatment, prevention and control
5. the Researcher with an interest in ESRD and RRT.
6. the press and the public.

About MOSS.....

Cadaver organ transplantation activity has noticeably increased in the last decade in Malaysia. A recurring issue of concern was how and to whom cadaver organs are allocated. In 1999, the Malaysian Society of Nephrology (MSN) had established a committee, which was tasked to initiate the development of a national organ-sharing network. The network was referred as the Malaysian Organ Sharing System or MOSS in short, and the committee was thus named MOSS committee

The functions of the MOSS committee thus established then under MSN were to:

1. Make policy decision concerning MOSS.
2. Secure funding from various sources to support MOSS operation.
3. Designate a place to be the coordinating centre for the operation of MOSS.
4. Canvass the views of nephrologist and other clinical staff involved concerning the policy and operation of MOSS.
5. Oversee the operation of the MOSS.
6. Employ a manager and other necessary support personnel to manage the day-to-day operation of the MOSS.
7. Appoint panel of nephrologist to examine eligibility of potential recipients

The objectives of MOSS in turn as established by MOSS Committee were:

1. To maintain a list of patients who have voluntarily enrolled as potential recipients in the cadaveric kidney transplantation program
2. To prioritise the waiting list according to an agreed criteria and scoring system
3. To update the waiting lists at periodic intervals according to specified criteria
4. To provide a list of suitably matched potential recipients based on agreed criteria when a cadaver organ is available
5. To prepare an annual report of the status of the cadaveric kidney transplantation program including the waiting list, donor status and outcomes

The National Renal Registry (NRR), which was then sponsored by MSN, was directed to assist in the setting up of MOSS and to make available its database to support MOSS operations. From this database, a transplant waiting list was generated and indeed was in use.

However, the subsequent operations of MOSS such as in entering new patients into the list, maintaining and updating the list, updating patient's information and so on, turned out to be logistically more difficult than had been expected. Over the years, various manual systems and procedures had been tried to coordinate and support the activities of the various parties involved in the transplantation process. In particular:

1. The nephrologist caring for dialysis patients who are potential recipients need to be able to efficiently put their patients on the list, update their patients' data, and take them off the list temporarily or otherwise when necessary.
2. The Transplant Centre performing the transplant surgery obviously need timely access to the recipient wait list that is ranked according to pre-determined criteria, as

well as to access their contact information in order to inform patients to come forward for transplant when an organ becomes available. At the same time, the transplant surgeon will want to review the selected patients' clinical information relevant to the transplant surgery.

3. The National Renal Registry is the channel through which nephrologists or dialysis centres notify patients in order to put patients on the wait list.
4. And finally, the MOSS Committee needs to be able to convey its policy and operational decisions to users, such as on assigning patients to nephrologist for purpose of managing their wait list status, adjudication on patient eligibility for transplant and their ranking on the list, final decision on entry into the SOS list.

In early 2004, the MOSS Committee proposed to MSN council to support the development of a web based system, named eMOSS, to support the operations of MOSS. The nature of MOSS operations, involving multiple parties spread throughout the country was ideally suited for web-based automation. The proposal was accepted and funds allocated for the development. The NRR and the Clinical Research Centre (CRC) were tasked with undertaking this project, and also to help fund it in part.

eMOSS website is allocated in <http://msn.org.my> . You may download a copy of the user manual from the website. This website is reinforced with high security. There are pre-set rules to access right according to the approved guideline. Access to the patients information is however restricted to authorized and designated users only. To get your password please contact the MOSS coordinator at e-mail: moos@msn.org.my.

Contributing Editors

Chapter Title	Editors	Institution/company
Chapter 1: Renal Replacement Therapy in Malaysia	Lim Yam Ngo	Kuala Lumpur Hospital
	Lim Teck Onn	Clinical Research Centre, KL
Chapter 2: Dialysis in Malaysia	Lim Yam Ngo	Kuala Lumpur Hospital
	Lim Teck Onn	Clinical Research Centre, KL
Chapter 3: Death and Survival on Dialysis	Wong Hin Seng	Kuala Lumpur Hospital
	Ong Loke Meng	Penang Hospital
	Wan Shaariah Bt Md Yusuf	Seremban Hospital
Chapter 4: Quality of Life and Rehabilitation Outcome of Dialysis Patients	Liu Wen Jiun	Sultanah Aminah Hospital, JB
	Alinda Chiu Sze Fung	Kuala Lumpur Hospital
	Chew Thian Fook	Seremban Hospital
	Zaki Morad B Mohd Zaher	Kuala Lumpur Hospital
Chapter 5: Paediatric Renal Replacement Therapy	Lee Ming Lee	Seremban Hospital
	Susan Pee	Sultanah Aminah Hospital, JB
	Lynster Liaw	Penang Hospital
	Wan Jazilah Wan Ismail	Selayang Hospital
	Lim Yam Ngo	Kuala Lumpur Hospital
Chapter 6: Management of Anaemia in Dialysis Patients	Philip N. Jeremiah	Ampang Puteri Hospital, KL
	Bee Boon Cheak	Selayang Hospital
Chapter 7: Nutritional Status on Dialysis	Ahmad Fauzi Abdul Rahman Tilakavati Karupaiah	Puteri Specialist Hospital, JB Universiti Kebangsaan Malaysia
Chapter 8: Blood Pressure Control and Dyslipidaemia	S. Prasad Menon Lee Wan Tin	Subang Jaya Medical Centre
Chapter 9: Management of Renal Bone Disease in Dialysis Patients	Fan Kin Sing	Gleneagles Intan Medical Centre, KL
	Rozina Bt Ghazalli	Penang Hospital
	Shahnaz Shah Firdaus Khan	Tg. Ampuan Rahimah Hospital, Klang

Chapter 10: Hepatitis on
Dialysis

Teo Sue Mei
Claire Tan Hui Hong
Foo Sui Mei
Indralingam Vaithiligam

Ipoh Hospital
Sarawak Hospital
Ipoh Hospital
Taiping Hospital

Chapter 11 Haemodialysis
Practices

Tan Chwee Choon
Tharmaratnam A/L Rasanayagam
Shahnaz Shah Firdaus Khan

Tg. Ampuan Rahimah Hospital, Klang

Chapter 12: Chronic
Peritoneal Dialysis Practices

Chang Sean Haw

University Malaya Medical Centre

Chapter 13: Renal Transplant

Goh Bak Leong
Zaki Morad B Mohd Zaher
Rohan Malek
Fan Kin Sing
Prasad Menon
Tan Si Yen
Lily Mushahar

Serdang Hospital
Kuala Lumpur Hospital
Selayang Hospital
Gleneagles Intan Medical Centre, KL
Subang Jaya Medical Centre
University Malaya Medical Centre
Selayang Hospital

FOREWORD

This report of the National Renal Registry continues to document the growth in the dialysis population. This growth has been contributed by providers from three sectors almost equally ie the public sector, the private sector and the non governmental organisations which are in the main charitable organisations. The government has remained the main funding agency for dialysis treatment. This unique arrangement is seen only in a few countries and in this country has served us well.

The most consistent growth has been with Hemodialysis (HD) treatment. Continuous Ambulatory Peritoneal Dialysis (CAPD) which has been available in this country for more than 20 years has yet to find its optimal position in the overall provision of renal replacement therapy (RRT). Many nephrologists feel that CAPD should have a greater share of the “RRT market”. Presently CAPD is available only in public sector institutions. A cost effectiveness study reported in the last issue of the Registry’s report showed that there is no difference in the cost per life year saved between HD and CAPD. In this report as was in the previous one, Quality of Life scores were higher in CAPD compared to hemodialysis patients. The perception that CAPD is more expensive than HD has led to many doctors not actively advocating this dialysis modality, despite its advantage as a home based self-care treatment. This report also showed that the death rate for CAPD has levelled off in the last few years reflecting perhaps the use of better systems, greater experience and expertise in the care of these patients.

Renal transplantation rate has remained low for many years. The easy accessibility to dialysis may have worked against renal transplantation. In the early years of RRT program in this country a patient did not get on to dialysis unless he has a potential living related donor. The easy access to cadaveric transplantation in China has also served as a disincentive for the living related renal transplantation program. The efforts to educate the public and healthcare givers will have to continue. The nephrologists managing newly diagnosed ESRD patients should actively promote kidney transplantation particularly among the younger patients.

While the growth has been laudable, a number of issues and challenges are seen as a result of the rapid expansion. Significant variation in practices was noted and is of some concern as they can lead to differing outcomes. Blood flow rates, frequency of dialysis and prescribed Kt/V are amongst parameters shown to vary and all of these have an impact on the adequacy of dialysis. The registry has undertaken to provide individual centre’s report which captures key parameters in the provision of dialysis treatment. Centres can evaluate their performance and compare with the national average and take steps to correct any deficiencies. Such a step hopefully will lead to better outcomes in the future. Why does such a variation in practice occur? One possible explanation is the heterogeneous background of the providers. Apart from large institutions like the Ministry of Health, most of the other providers are stand-alone units. They may have different approaches to treatment. A more likely reason is the many constraints faced by the NGO centres. They include finance, expertise and other resources

Both doctors and nursing staff should take cognisance of these “gaps” in practice and in outcomes. More detailed studies may need to be done to determine the factors that lead to these “gaps” and the remedial actions that have to be taken. The registry is the repository of a lot of information that can be utilised for these types of studies and the committee welcomes interested individuals to undertake them.

I would like to thank all contributors for their continued support. I would also like to extend the committee's thanks to the editors Drs Lim Yam Ngo and Lim Teck Onn as well as the Manager Ms Lee Day Guat for their untiring efforts in ensuring the report is produced. We have endeavoured to make the report a readable and informative one which will be of use to all parties.

Zaki Morad Mohd Zaher
Chairman,
National Renal Registry
Malaysian Society of Nephrology