

**Directory of Dialysis Centres**  
**in**  
**MALAYSIA**  
**2005**

**National Renal Registry**

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### ***Abbreviations***

CAPD	Continuous Ambulatory Peritoneal Dialysis
CRA	Clinical Registry Assistant
CRC	Clinical Research Centre
CRM	Clinical Registry Manager
ADMAN	Association of Dialysis Medical Assistant and Nurses
ESRD	End Stage Renal Disease
eMOSS	Malaysian Organ Sharing System _Renal web application
MSN	Malaysian Society of Nephrology
MOSS	Malaysian Organ Sharing System
NRR	National Renal Registry
RRT	Renal replacement therapy
SDP	Source data producer
TX	Transplant

### ***Glossary***

Advisory Committee	A board, council, panel or group thereof that is established by the sponsors of the registry to oversee the operations of the MOSS/NRR.
Advisory Committee Member	An individual appointed to serve in the Advisory Committee. Members may have relevant expertise and/or represent the interest of Source data producers (SDP), users or donor.
Collaborating Unit	The organization designated by the Advisory Committee to provide the functional capacity to support the registry operations. This includes the collection, and analysis of data, and feedback of information to users. The unit is typically staffed by Clinical Registry Manager, Clinical Registry Assistants, epidemiologist, statistician, information technology personnel and other supporting staff.
Source data producer	The individuals or institutions that report the required data to the registry

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## **NRR Advisory Committee Members**

**2004 to 2006**

### **MSN Nominees**

**CHAIRMAN:** Dato' 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

### **ADMAN Nominees**

**MEMBERS:** Mr. Tam Chong Chiang

Ms. Norlida Omar

**Secretariat** Ms. Lee Day Guat

### **NRR Office Staff**

**CRM** Ms. Lee Day Guat

**CRA** Ms. Mardhiah Arifin

Ms. Nor Azliana Ramli

### **CRC Technical Support Staff**

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**Head** Dr. Lim Teck Onn

**Epidemiologist** Dr. Jamaiyah Haniff

**IT Manager** Ms. Celine Tsai Pao Chien

**Database Administrator** Ms. Lim Jie Ying

Mr. Sebastian Thoo

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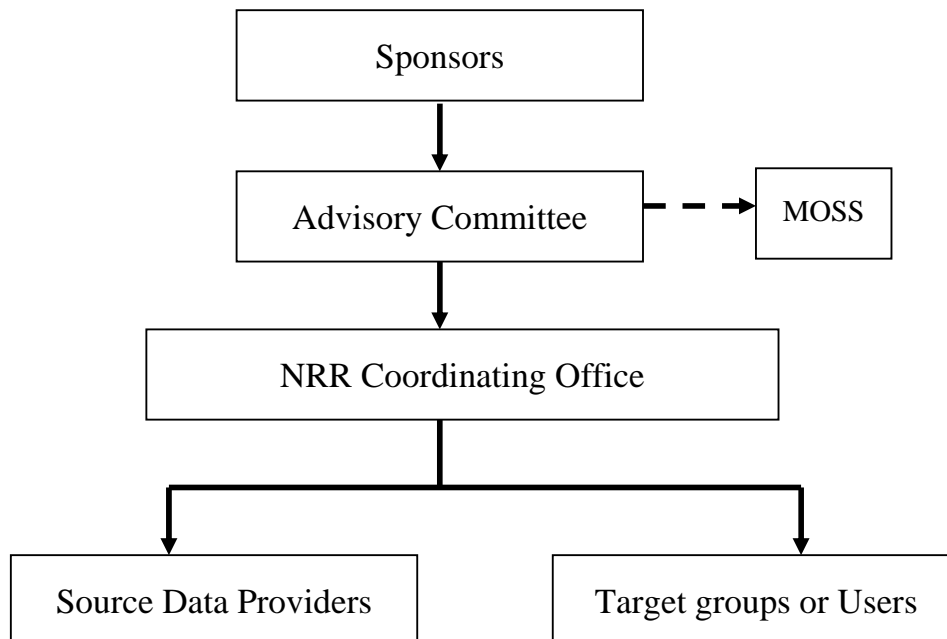
## About the National Renal Registry

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

### ***Advisory Committee.***

This is the committee established by the sponsor to oversee the operations of the registry and MOSS. Interested parties including source data producers, Renal Registry Unit and target groups or users are represented on this committee.

### ***National Renal Registry Coordinating Office***

The collection, and analysis of data, and feedback of information are performed in a single centre referred to as Renal Registry Unit (RRU). The Clinical Registry Manager (CRM) oversees the daily operation of the unit. The Clinical Research Unit of Hospital Kuala Lumpur with provides the support of the epidemiology, statistic and information technology.

### ***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 view 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 is then sponsor 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, turns 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 nephrologist 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 down load a copy of the user manual from the website. This website is reinforced with high security. There are pre-set rules to the access right according to the approved guideline. Access to the patients information is however restricted to authorized and designated user only. To get your password please contact the MOSS coordinator at e-mail: [moss@msn.org.my](mailto:moss@msn.org.my).

## ACKNOWLEDGEMENTS

The National Renal Registry would like to thank the following for their generous support:

### *Industry sponsors*

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Roche

### *Our advertisers*

*All the staff of the dialysis and transplant follow-up centres  
for their participation*

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Malaysia Society of Nephrology

### *Electronic version*

Electronic version of this directory can be downloaded at <http://www.msn.org.my/nrr>