

DIRECTORY OF DIALYSIS & TRANSPLANT CENTRES IN MALAYSIA 2008

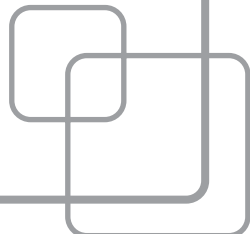


National Renal Registry

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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 _web application for renal
MSN	Malaysian Society of Nephrology
MOSS	Malaysian Organ Sharing System
MRRB	Malaysian Registry of Renal Biopsy
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 staffed by Clinical Registry Manager, Clinical Registry Assistants, epidemiologist, statistician, information technology personnel and other supporting staff.
Source data producer	The individual or institutions that report the required data to the registry

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

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***All who have in one way or
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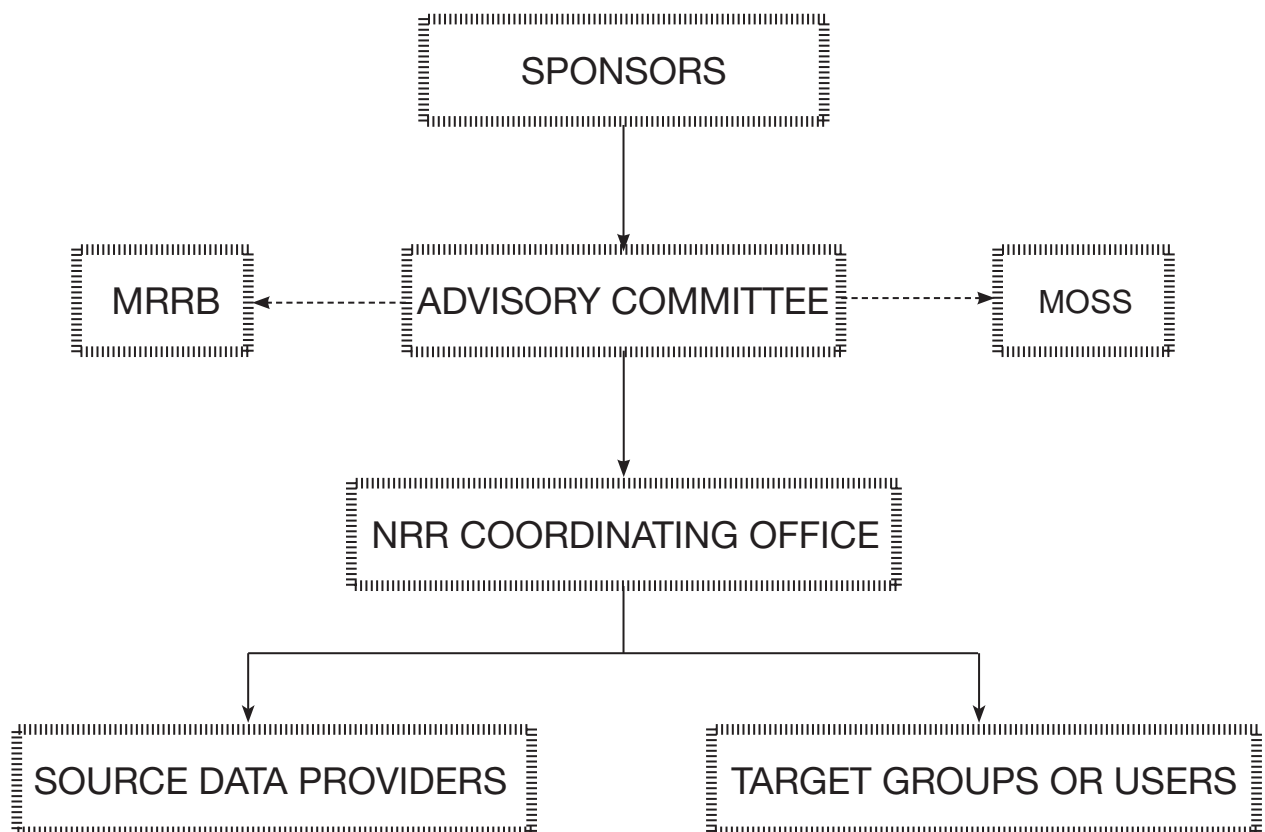
ABOUT THE NATIONAL RENAL REGISTRY

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 Association of 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 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 or 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

Malaysian Organ Sharing System or MOSS was started in 1997. In 2006, it was upgraded to a web application named e-MOSS and it was officially launched by Y. B. Dato Dr. Hj. Abd Latiff B Ahmad, the Deputy Minister of Health, Malaysia on 1st September 2006.

MOSS is managed by the MOSS committee established under the Malaysian Society of Nephrology (MSN) and National Renal Registry (NRR).

The objectives of e-MOSS

1. To maintain a list of patients who have voluntarily enrolled as potential recipients in the cadaveric kidney transplantation program in Malaysia.
2. To prioritise the waiting list according to an agreed criteria and its scoring system.
3. To update the waiting lists according to the specified criteria.
4. To enable cadaver organ to be allocated in a fair and equitable manner.
5. To facilitate centres to effectively manage their patients on the transplant waiting list

The functions of the MOSS committee are:

1. Make operational decisions concerning MOSS.
2. Secure funding to support its activities.
3. Secure views of nephrologists and other clinical staff regarding its policies and operations.
4. Identify nephrologists to assist in the potential recipient management.

The role of e-MOSS:

All patients registered with NRR will be included in the e-MOSS. However, the subsequent management of the patients' lists depends on the participating centres.

1. The doctor caring for dialysis patients who are potential recipients can now efficiently maintain their patients on the lists and update their patients' treatment information regularly.
2. The transplant coordinating centres can now access the potential recipients' listing that is ranked according to the pre-determined criteria. The patient could be easily contactable in the event of organ donation.

Participation in e-MOSS:

This system is located in a secured site; <https://www.macr.org.my/emoss>. There are link provided from <http://msn.org.my> or <http://msn.org.my/nrr>. All dialysis centres are welcome to be an e-MOSS user.

How to register with e-MOSS?

1. The dialysis centre needs to register as an e-MOSS user. Registration instruction and its documents are available in this web application.
2. Registered centre can nominate more users. However, the authorization must be from the centre's doctor in-charge.
3. All e-MOSS users need to complete a user agreement form and submit it to NRR for processing.

Management of e-MOSS

All patients registered with NRR shall be listed in the e-MOSS on the following day according to the criteria set in the e-MOSS. These are the listing where patients will be grouped:

1. SOS List
2. On Wait List
3. Auto Off List (Pending data update)
4. Temporary Off List
5. Pending Evaluation
6. Ineligible for transplant
7. Death and Transplanted

1. SOS List:

Patients on this list are given specially priority as they are expected to have a lifespan of less than a year unless renal transplantations are performed. Only nephrologists can request placement of patients into this list and a patient will only be placed into this list after approval is obtained from the MOSS Committee.

2. On Wait List

Patients listed here are patients who have met the criteria. These are the potential cadaver organ recipients.

3. Pending Evaluation

Potential eligible patients will be listed in the 'Pending List' upon registration with NRR. The doctor in-charge needs to assess the suitability of the patients for a transplant to enable the patient to be listed in the Wait list.

4. Temporary Off List

Doctor in charge should place the patient who is temporarily unfit for a transplant into this list so that he/she will not be contacted in the event of organ donation.

Transplant nephrologists will place the patient who is temporarily unfit for a transplant into this list if he/she is not fit for a transplant when contacted during the organ donation event.

5. Auto Off List (Pending data update)

If the participating centre did not submit the Annual Return (Haemodialysis & Peritoneal Dialysis) of a patient who is in the 'On Wait List', the system will automatically place the patient into this list. The patient in this list will not be eligible for organ transplantation.

The patient will be placed back into the "On wait list" subsequently if the serology results have been updated and the patient will not be penalized.

6. Ineligible for transplant

System auto lists those patients who do not meet e-MOSS criteria.

7. Death and Transplanted

These are patients who had a transplant and the graft is still functioning and those patients who had passed away.