

APPENDIX I:
Data Management

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Data Management

The Malaysian Registry of Renal Biopsy (MRRB) was established on the 1st January 2005. It started off as a pilot project involving centers with Nephrology services within the Ministry of Health Malaysia. In its infancy, this registry was called Glomerulonephritis (GN) Registry but subsequently changed to MRRB as it was deemed to be more appropriate.

The MRRB has gone through several enhancements in the data collection format in order to make it user friendly.

The operations of the MRRB are supported by an extensive ICT infrastructure to ensure operational efficiency and effectiveness. The MRRB data is stored in SQL Server and has a web-based application.

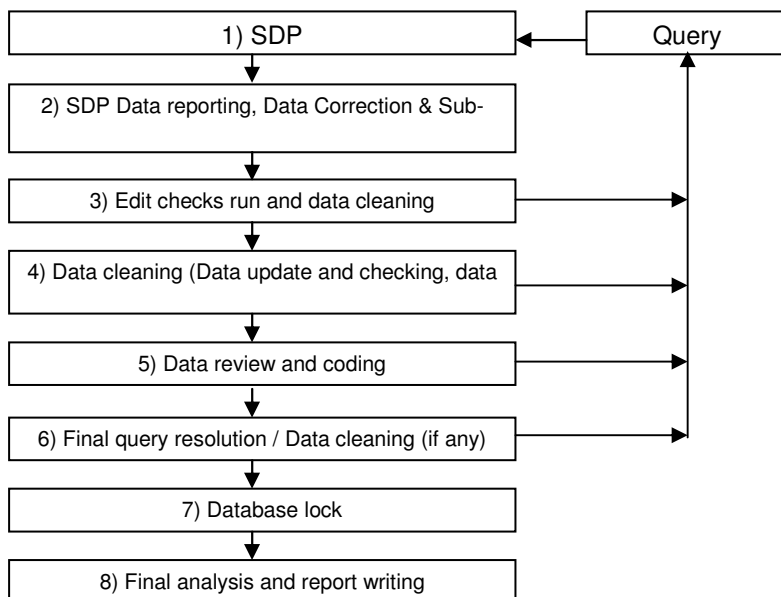
Data sources

Before the setting up of the MRRB, there were two separated databases in MOH related to renal biopsy. They are the paediatric (Institute Paediatric, HKL) renal biopsy database (1993 – 2004) and adult Department of Nephrology HKL renal biopsy database (2004-2005). The data from these databases had been mapped and incorporated into MRRB in 2005.

MRRB intends to be a national population-based registry and the participation is opened to all hospitals with nephrology services for renal biopsy throughout Malaysia.

Data flow process

This section describes the data management flow process of the Malaysian Registry of Renal Biopsy.



SDP

Nephrologist or renal physician who provides renal biopsy services in Malaysia.

SDP Data reporting, Data Correction and Submission tracking

Primary source data is reported by SDP via web applications e-Case Report Forms:

- MRRB Patient Notification form (Native Kidney Biopsy)
- MRRB Patient Notification form (Graft Kidney Biopsy)
- MRRB Biopsy Procedure form
- MRRB Outcome Notification form

The secondary data source is to determine both renal and mortality outcomes. Verification of both renal and mortality outcomes can be done through the Malaysian Dialysis and Transplant Registry and National Vital Registration System respectively.

Edit checks run and Data cleaning

Edit checks identify missing compulsory data, out of range values, inconsistent data, invalid values and error with de-duplication. Data cleaning is then performed based on the results of edit checks.

Data review and coding

Expert panels and registry manager performed data coding of free text description to its predetermined coding table or dictionary. The expert panel comprises of members with expertise and knowledge in the relevant area. They also perform Quality Control function on the assessment of coding. They ensure that complex medical data are reviewed and assessed to detect clinical nuances.

Final query resolution / data cleaning / database lock

A final edit check was performed to ensure that data is clean. All queries were resolved before database is locked to ensure data quality and integrity. Final dataset is subsequently locked and exported to statistician for analysis.

Data release and publication policy

The MRRB is part of the National Renal Registry (NRR), which is owned by the Malaysian Society of Nephrology (MSN). One of the primary objectives of the Registry is to make data available to the renal community. The registry's published report is available on the website <http://www.msn.org.my/nrr> or <https://www.macr.org.my/emrrb>. The report is copyrighted. However it may be freely reproduced without the permission of the National Renal Registry, Malaysia. Acknowledgement would be appreciated. Suggested citation is: Rosnawati Y, Wan Jazilah WI (Eds), Second Report of the Malaysian Registry of Renal Biopsy 2008 Kuala Lumpur 2010.

The Registry encourages original research and publication using MRRB data in part or full. Any request for raw data or aggregated data must be made in writing (by e-mail, fax, or registered mail). The researcher is required to submit a completed Data Release Application Form and signed Data Release Agreement Form, accompanied with a study proposal / mock tables. Such request will require approval from NRR Advisory Board.

NRR position as follows:

- The NRR does not envisage independent individual publication based entirely on NRR published results, without further analyses or additional data collection.
- NRR however agrees that investigator shall have the right to publish any information or material arising in part out of NRR work. In other words, there must be additional original contribution by the investigator in the work intended for publication.
- NRR encourages the use of its data for research purpose. Any proposed publication or presentation (e.g. manuscript, abstract or poster) for submission to journal or scientific meeting that is based in part or entirely on NRR data should be sent to the NRR prior to submission. NRR will undertake to comment on such documents within 4 weeks. Acknowledgement of the source of the data would also be appreciated.
- Any formal publication of a research based in part or entirely on NRR data in which the input of NRR exceeded that of conventional data management and provision will be considered as a joint publication by investigator and the appropriate NRR personnel.

The Malaysian Society of Nephrology has made a grant towards the cost of running the registry and the report printing to allow distribution to all members of the association and the source data producers. The report will also be distributed to relevant Health Authorities and international registries.

Further copies of the report can be made available with donation of RM60.00 to defray the cost of printing. The full report is also available in the registry web site www.msn.org.my/nrr.

