

Utilisation of National Renal Registry in Clinical Research in Malaysia

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ABSTRACT

Summary: Registries provide consistent data for defined populations and can be used to support the study of the determinants and manifestations of disease and provide a picture of the natural history, outcomes of treatment, and experiences of individuals with a given condition or exposure. The use of disease registries for clinical studies has become increasingly common and has led to advancements in the understanding of many disease processes. The availability of demographic and disease characteristic data on large patient populations, coupled with the minimal cost and relative speed of conducting retrospective investigations, provide an attractive alternative to original data collection. However, one must be aware of the limitations inherent to the data collection process for registry which may result in the reduction of generalizability and introduce bias. One of the most important activities with greatest impact on the field of nephrology in this country is the formation of National Renal Registry (NRR), which was initially started by the pioneering nephrologists and paramedics in Hospital Kuala Lumpur. This was subsequently adopted by Malaysian Society of Nephrology which is the umbrella body to better represent the nephrology and dialysis communities for the whole country. The idea of a National Dialysis and Transplant Registry was mooted in the late 80's and early 90's with the purpose of formally looking at the data and evaluating the performance and outcomes in treating patients with end stage kidney disease. This was an important effort taken by the early pioneers who believed in continuous auditing and assessing the quality of care, besides providing invaluable information to health care providers, policy makers as well as industries. The pioneering nephrologists were keenly aware that the high cost of dialysis will come under close scrutiny of the public and policy makers due to the ever escalating cost of health care and budgetary constraints. This was coupled with the rapid expansion of private and non-governmental organization (NGO) haemodialysis facilities. Concerns about the quality and standards of treatment provided can only be reliably monitor with good and reliable data such as NRR. The first NRR Report published in 1993 was mainly focused on the dialysis programme run by Ministry of Health. In the subsequent years, data from all dialysis units in the private, NGOs and public sectors were collected to mark the beginning of a truly "National" renal registry. Following the success of NRR, there were other offshoot or siblings of NRR developed subsequently which played equally important roles and contribution to the nephrology communities in this country. The 1st report of Malaysian Registry of Renal Biopsy was published in 2007. Another important offshoot of NRR is eMOSS which was initially established in 1999 and converted to e-version in 2006. Over the last 25 years, NRR had not only produced the annual report for local consumption but also contributed data annually to many international organisations including US Renal Data System (USRDS) and the Global Observatory on Organ Donation and Transplantation (GODT). Over the years, data from MDTR were used by professionals for research and publications, students and trainees for various professional program, basic degree, Masters and PhD thesis in Malaysia. NRR has also assisted the setting up of Brunei Dialysis and Transplant Registry (BDTR) as well as the South Africa Renal Registry. Reports from NRR on dialysis and transplantation became the basis for Q&A sessions in the Malaysian Parliament while occasional reviews and reports by the print, electronic and alternative media on Chronic Kidney Disease often cite local data traceable to the Annual MDTR reports.