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The Development and Experiences of Informatics System for Renal Registry in Taiwan What's able? and What's unable?

Shang-Jyh Hwang
Kaohsiung Medical University Hospital, Kaohsiung, Taiwan

The Taiwan dialysis registry was developed in 1987 by Prof. TS Yuan, Chairman of Dialysis Committee of TSN, for surveying dialysis units and numbers of dialysis patients in Taiwan. Initially, it was accomplished by paper works from each dialysis unit and renewed every year with repetitively hard works and imperfect results. The collected parameters were simply for basic registry report. In 1995, the contents of registry for HD/PD patients and dialysis unit were reformed extensively to include laboratory and quality parameters for registry report and for data analysis.

In 1996, TSN launched a custom-made computer software (1st version) to collect dialysis data. Promotion and instruction how to use computer and software were the major tasks and burdens at that time. This prototype software was soon replaced by the 2nd version, the TSN-HOPE-2000 System. HOPE system was designed and accomplished through a team work including nephrologists, software engineer, and coordinators. The time-based clinical course flowchart for each patient from entering HD/PD to the end of life was the main change in design. Using the software to input patient basic information, collecting data of dialysis treatment, monthly laboratory, hospitalizations, functional status, and outcomes were promoted. All the data of last year must be done and sent to TSN through disc or internet (later). The TSN combined all the data and made thoroughly cleaning works by the assistance of the Statistic Company. The clean datasets were analyzed by a team of statisticians, nephrologists, and epidemiologists for annual data report and published in *Acta Nephrologica* under the collaboration with the National Health Research Institute.

As the progress in informatics technology, a new version TSN-KiDiT software was launched to replace the HOPE-2000 in 2012. The new software was an Internet based design for program renew and data transmission, and also designed to collect information of CKD and renal transplant patients. However, these parts are not completed yet. Thus the data of CKD and renal transplant patients are obtained from NIH datasets now. The efficiency of software must keep improving based on the clinical flowchart, requirements from dialysis units, and the regulations from National Health Insurance for dialysis payment reimbursement.

In conclusion, the keys of success for renal registry are cooperative, considerate, efficient, and functioning teamwork from a group of devoted team members.