# Japanese society for dialysis therapy renal data registry—a window through which we can view the details of Japanese dialysis population

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**The Japanese Society for Dialysis Therapy (JSDT) collects the clinical data from all the facilities to create a nation-wide registry system named JSDT Renal Data Registry (JRDR). This survey was begun in 1966 as a form of facility survey. Patient survey started in 1983. More than 95% of facilities respond to the survey on the basis of voluntary work of facility staffs. Therefore, JRDR has the longest history and the most comprehensive coverage. As for the prevalent patients, 304,856 patients are treated by dialysis therapy in Japan as of the year 2011. The demographics of the Japanese dialysis population have been markedly changing in terms of age, primary diagnoses and dialysis vintage. The mean age of prevalent population reaches 66.55 years at the end of 2011. The increase in the numbers of dialysis population is due to the growth of those older than 65 years old. Patients with the vintage longer than 20 years account for 8% of the entire population. Around 38 thousands patients started their dialysis treatments, whereas 31 thousands deceased. The disease burden of cardiovascular diseases as well as infection is substantial due to the demographic changes. Many evidences have been reported from the data obtained from JRDR to date. These findings covers a wide range of dialysis practice and are utilized for the development of JSDT guidelines. Therefore, JRDR has provided indispensable and fundamental data of Japanese dialysis population.**

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## OVERVIEW OF JRDR

Japanese Society for Dialysis Therapy (JSDT) has been performing a survey of dialysis patients as well as dialysis facilities in Japan annually. JSDT develops a nation-wide registry system from thus collected data, named 'JSDT Renal Data Registry (JRDR)'. In this article, we review the overview of JRDR, several important findings derived from the registry and significance of JRDR.

### History of JRDR

In 1963, the first chronic hemodialysis (HD) therapy was performed in Japan.[1] In 1966, 3 years after the first chronic HD therapy, annual survey as a form of facility survey was started. In 1983, 20 years after the first HD therapy in Japan, the current survey system designed for individual patient was implemented.[1] Thereafter, although some modifications, mostly concerning items to be collected, were made, the overall system has remained the same.

### Data collection methods

JSDT headquarters send questionnaires every November to all dialysis facilities where patients receive dialysis treatment. Thereafter, the staffs at each dialysis facility fill the questionnaires with the data of all patients at the end of every year on the basis of totally voluntary work of the staffs at each facility. And they send them back to the JSDT headquarters.

There are two forms of questionnaires: one is a paper version and the other is an electrical version, which was implemented in 1994. Both include facility survey and the critical data in patient survey in common; the latter contains patient demographics, outcomes, comorbidities, and important clinical conditions. The electrical version as a form of Microsoft Excel (Microsoft Corporation, Redmond, WA, USA) collects more detailed data (Appendix indicates items that were collected at the end of 2013).[2]

### Facility survey and patient survey

Questionnaires consist of facility survey and patient survey.

Facility survey comprises the data of each facility and includes such parameters as numbers of patients, modality, numbers of staffs in charge of dialysis patients, and status of water purification (Appendix).

Patient survey collects these data for individual patients. The patients to be investigated are all of the patients who are treated by dialysis at any moment during the year.

Patient survey includes data as follows: (1) demographic data such as anonymized name, sex, date of birth, month of initiation, primary diagnosis, and place of living; (2) modalities of therapies, such as HD, hemodiafiltration, or peritoneal dialysis (PD); (3) outcomes such as death, transplantation or withdrawal, and the occurrence of cardiovascular events and fracture; (4) outcome-relating factors such as body size, urea, creatinine, mineral bone disorder (MBD) markers, anemia, blood pressure, and pulse rate; (5) PD relating data including PD prescription, dialysis dose, the results of peritoneal equilibration test, and infection rate only for PD patients.

Figure 1 indicates the trend of response rate for facility survey and patient survey, as well as facility numbers. Facility numbers themselves are increasing steadily and exceeded 4000 past several years. The response rates have been around 95% for patient survey and more than 98% for facility survey. Therefore, JRDR a is comprehensive survey of the Japanese dialysis population.

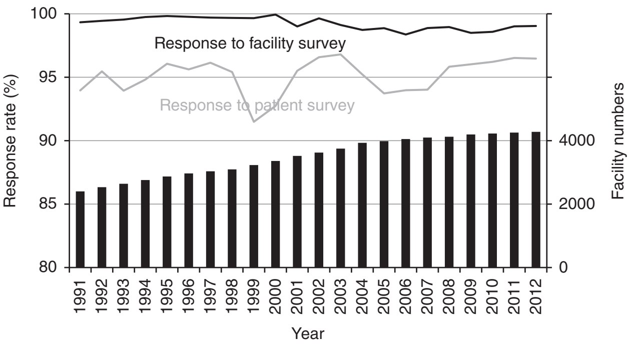

**Figure 1 | Trend of response rate and facility numbers.** Facility numbers themselves are increasing steadily and exceeded 4000 in the past several years. About 95% of total facilities responded to patient survey. Moreover, more than 98% of facilities responded to facility survey. This figure was modified from the data that appeared in the preface of the Japanese version of the annual report of each year with permission of CRDR. CRDR, The Committee of Renal Data Registry of the Japanese Society for Dialysis Therapy.

## DEMOGRAPHICS OF THE JAPANESE DIALYSIS POPULATION AND THEIR CHANGE

***Overview of the Japanese dialysis population*.** As of 2011, 304,856 patients were receiving dialysis therapies.[2] This figure corresponds to 2385.4 patients per million of general population. The numbers of facilities that responded to the survey was 4213. More than 125 thousands of dialysis machines existed in Japan.

During the year 2011, 38,613 patients started their dialysis and 30,743 patients deceased. The number of deceased patients has been continuously increasing, whereas the number of incident patients almost remains the same during the past several years. The differences of these two figures correspond to the annual increase in dialysis population. Therefore, the increase in the dialysis population becomes dull.

Most of patients as much as 97% of total dialysis population receive HD, whereas the remaining 3.2% (9642 patients) are treated by PD. Although only 0.1% (327 patients) receives home-based HD, the population treated by home-based HD is growing sharply during the past several years.

The male patients are more predominant (62.6% of total population) than female patients for all vintage groups. However, the differences become smaller for the patients with longer vintage, e.g., male patients account for 54.2% of those who have been treated for more than 25 years. The fact might indicate that the survival is better among female patients.

Dialysis population is rapidly aging. The average ages of dialysis patients were 46.23 years for prevalent patients and 50.05 years for incident patients in 1981.[3] The average age of the incident population was 67.84 years, and prevalent population was 66.55 years as of 2011.

The most prevalent age group is 60–64 years for male and female prevalent patients (Figure 2a). The former is the reflection of baby boomers. The proportion of elderly over 75 was larger for female (32.8%) than male (26.0%). On the

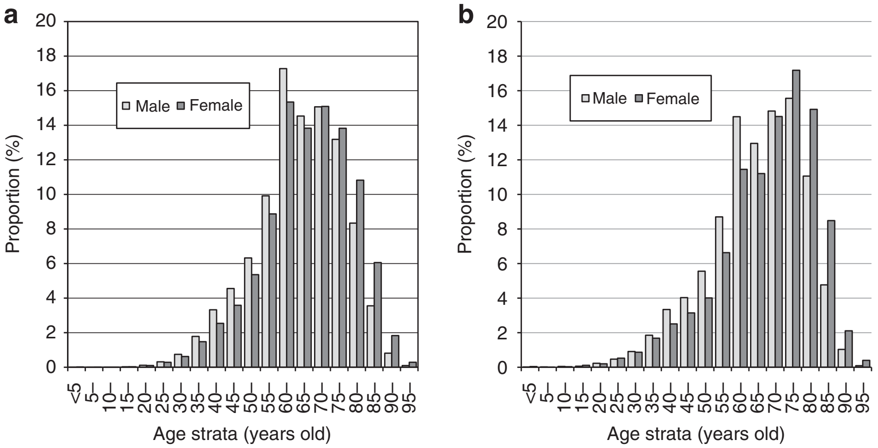

**Figure 2 | Distribution of the patients by age strata.** (**a**) For prevalent patients, the mode of age strata is 60–64 years both for male and and female patients. The proportion was larger for female patients over 75 years of age. (**b**) For incident population, 75–79 years old strata are the most populous for both male and female patients. Pale bar and filled bar represent male and female patients, respectively.