

Data item collection by renal registries around the world

Results of the SharE-RR survey

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Introduction

In 2017 the ISN established 'Sharing Expertise to support the set-up of Renal Registries' (SharE-RR) to help countries develop a registry. A survey was circulated to registries worldwide to collect a range of information, including which data items are collected by renal registries.

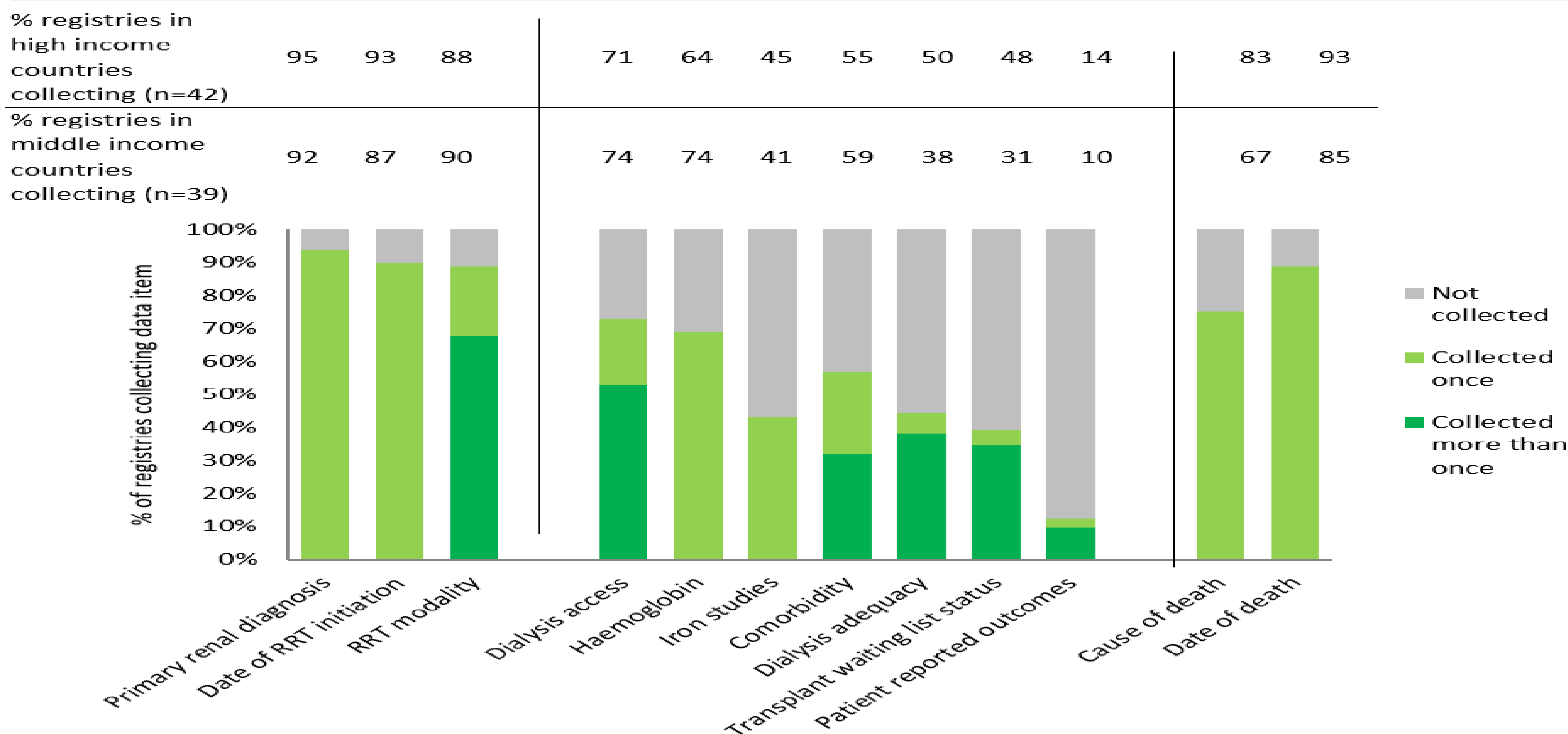
Understanding the extent of kidney disease, access to treatment, standards of care and patient outcomes require the collection of appropriate, high quality data.

Methods

The SharE-RR survey (SurveyMonkey, English language only) was piloted and developed iteratively with 6 registries in 3 continents. In 2018 the survey was emailed to 126 registry contacts provided by Share-RR team members. The focus of this study is 41 data items relevant to haemodialysis. Economic wealth was assessed using the World Bank classification of countries.

Results

Of 91 contacts who responded (72% response rate), 85 submitted a survey on behalf of their registry. 81 surveys were included in this study (3 excluded because incomplete, including the sole low income country; 1 excluded because HD data not collected). A selection of data items is displayed to show the breadth and variation of data collection and to explore any relationship between economic wealth and data collection.



Conclusion

Renal registries differ in the breadth of data items that they collect. Data collection is likely to be influenced by local economic environment, for example, the availability of staff to collect data and an IT infrastructure to facilitate data collection. Our findings suggest that once established, registries collect a core dataset irrespective of economic wealth, although further work is needed to understand the impact such factors have on the ability of a registry to collect and report data, particularly in low income countries.

On behalf of the SharE-RR Project:

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