Global coverage of health information systems for kidney disease: availability, challenges, and opportunities for development

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Development and planning of health care services requires robust health information systems to define the burden of disease, inform policy development, and identify opportunities to improve service provision. The global coverage of kidney disease health information systems has not been well reported, despite their potential to enhance care. As part of the Global Kidney Health Atlas, a cross-sectional survey conducted by the International Society of Nephrology, data were collected from 117 United Nations member states on the coverage and scope of kidney disease health information systems and surveillance practices. Dialysis and transplant registries were more common in high-income countries. Few countries reported having nondialysis chronic kidney disease and acute kidney injury registries. Although 62% of countries overall could estimate their prevalence of chronic kidney disease, less than 24% of low-income countries had access to the same data. Almost all countries offered chronic kidney disease testing to patients with diabetes and hypertension, but few to high-risk ethnic groups. Two-thirds of countries were unable to determine their burden of acute kidney injury. Given the substantial heterogeneity in the availability of health information

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systems, especially in low-income countries and across nondialysis chronic kidney disease and acute kidney injury, a global framework for prioritizing development of these systems in areas of greatest need is warranted.

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Health information systems are the cornerstone of health service surveillance and monitoring, governance and regulation, and planning and development.[1] Encompassing registries, electronic health records, and disease surveillance systems, health information systems provide an overview of disease incidence, prevalence and patient outcomes,[2,3] allow the objective assessment of the quality and safety of care,[4,5] and facilitate comparisons between and within health services.[3,6–9] Health information systems have become essential for informing health service growth and expansion,[10,11] enabling policy development,[11,12] stimulating research and hypothesis generation,[13–15] and guiding allocation of resources and funding.[16,17]

All countries can benefit from comprehensive health information systems. For high-income countries, such systems can provide a cost-effective means by which to identify, implement, and share best practices,[2,11] and potentially to reduce health care costs by identifying areas with unduly high or unnecessary expenditures.[2] Additional benefits for low-income countries include identification of areas of need to enable prioritization, and appropriate channeling of health care resources.[18] Despite these benefits, there is significant heterogeneity in the global availability of health information systems,[19,20] which is unsurprising given the financial and organizational resources required to establish such systems.

The global coverage of health information systems across the spectrum of kidney disease has not been well described. Liu *et al.* reported global variability in the availability and scope of dialysis-specific renal registries.[21] In their review, they found 48 dialysis registries, almost half of which were based in Europe. Most did not record clinical outcomes other than mortality, and public access to information was uncommon. Similar issues undoubtedly exist in transplantation, nondialysis chronic kidney disease (CKD), and acute kidney injury (AKI) registries. Identification of deficiencies in the global coverage of kidney disease health information systems will facilitate targeted improvement in areas of need. In turn, an accurate estimation of the global burden of kidney disease will be achievable and regional, national, and global resources can be focused appropriately.

Results

Of the 130 United Nations member states that received an invitation to participate, 125 states completed 227 surveys. In total, 117 states provided information pertaining to their kidney disease health information systems, with representation across all International Society of Nephrology (ISN) regions and 2014 World Bank country classifications (i.e., low-, lower-middle–, upper-middle–, and high-income).[22,23] Most of the 227 survey respondents were nephrologists ($n = 202$, 89%), followed by health care administrators or policy makers ($n = 9$, 4%), non-nephrology physicians ($n = 7$, 3%), and other individuals ($n = 9$, 4%).

Availability of registries. The majority of countries ($n = 75$, 64%) reported the existence of a national or regional registry for dialysis, and over half ($n = 68$, 58%) had a registry for transplantation. There was wide variation between ISN regions and World Bank income groups in terms of dialysis and transplant registry availability, with the lowest representation in low-income countries in Africa, the Middle East, and South Asia (Table 1, Figures 1 and 2). Most high-income countries had a dialysis ($n = 34$, 89%) or transplant registry ($n = 34$, 89%). Few low-income countries had a dialysis registry ($n = 3$, 18%), and none had a transplant registry. Only 9 (8%) countries had a nondialysis CKD registry and 8 (7%) an AKI registry, with little variation across ISN regions and World Bank income groups (Figure 2). The majority of nondialysis CKD registries ($n = 5$, 56%) covered all stages of CKD and were based nationally ($n = 8$, 89%). Mandatory provider participation was required for most dialysis ($n = 40$, 54%), transplant ($n = 39$, 57%) and nondialysis CKD ($n = 5$, 63%) registries; however, AKI registries tended to be voluntary ($n = 4$, 50%) (Figure 3).

CKD incidence and prevalence. According to respondents from about two-thirds of countries, data were available on national prevalence of CKD ($n = 72$, 62%) (Table 2, Figure 4). Although CKD prevalence data were available in most lower-middle– ($n = 21$, 64%), upper-middle– ($n = 21$, 70%), and high-income ($n = 26$, 68%) countries, only a small number of low-income countries ($n = 4$, 25%) reported access to the same information. One-quarter ($n = 32$, 27%) of countries identified ethnic groups at high-risk of CKD in their countries, of which very few were low-income countries ($n = 3$, 19%).

Identification of CKD. A total of 28 (24%) countries had an established population-based CKD screening program for individuals without specific CKD risk factors; most were in high-income countries ($n = 12$, 32%). The only low-income country with a CKD screening program implemented it actively through both routine health encounters and specific screening processes. Lower-middle–income countries tended to use active screening more often than reactive screening (50% vs. 25%), while upper-middle– and high-income countries used both active and reactive approaches equally.

Countries varied in their approach to CKD testing in high-risk individuals (Table 3). All countries performed CKD testing through routine health encounters in patients with diabetes mellitus, and almost all ($n = 113$, 97%) did so in those with hypertension. Approximately 80% of countries tested patients with a history of cardiovascular disease,