

# Guidelines, policies, and barriers to kidney care: findings from a global survey



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An international survey led by the International Society of Nephrology in 2016 assessed the current capacity of kidney care worldwide. To better understand how governance and leadership guide kidney care, items pertinent to government priority, advocacy, and guidelines, among others, were examined. Of the 116 responding countries, 36% ( $n = 42$ ) reported CKD as a government health care priority, which was associated with having an advocacy group ( $\chi^2 = 11.57$ ;  $P = 0.001$ ). Nearly one-half (42%; 49 of 116) of countries reported an advocacy group for CKD, compared with only 19% (21 of 112) for AKI. Over one-half (59%; 68 of 116) of countries had a noncommunicable disease strategy. Similarly, 44% (48 of 109), 55% (57 of 104), and 47% (47 of 101) of countries had a strategy for nondialysis CKD, chronic dialysis, and kidney transplantation, respectively. Nearly one-half (49%; 57 of 116) reported a strategy for AKI. Most countries (79%; 92 of 116) had access to CKD guidelines and just over one-half (53%; 61

of 116) reported guidelines for AKI. Awareness and adoption of guidelines were low among nonnephrologist physicians. Identified barriers to kidney care were factors related to patients, such as knowledge and attitude (91%; 100 of 110), physicians (84%; 92 of 110), and geography (74%; 81 of 110). Specific to renal replacement therapy, patients and geography were similarly identified as a barrier in 78% (90 of 116) and 71% (82 of 116) of countries, respectively, with the addition of nephrologists (72%; 83 of 116) and the health care system (73%; 85 of 116). These findings inform how kidney care is currently governed globally. Ensuring that guidelines are feasible and distributed appropriately is important to enhancing their adoption, particularly in primary care. Furthermore, increasing advocacy and government priority, especially for AKI, may increase awareness and strategies to better guide kidney care.

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Leadership and governance are essential for overseeing and guiding an effective health care system.<sup>1</sup> Leadership directs the strategic vision and facilitates progress through appropriate resource management,<sup>2</sup> and governance encourages consistency and accountability.<sup>3</sup> Together, leadership and governance create awareness, develop strategies, set priorities, and generate consistent, sustainable, and accountable action. In kidney care, effective and sustainable leadership and governance are pertinent for the development of high-quality programs, as well as for raising awareness and developing action plans for universal access to care, a globally recognized priority of any health care system.<sup>4</sup> Acute kidney injury (AKI) and chronic kidney disease (CKD) are conditions with considerable public health implications due to associations with adverse health outcomes and high health care costs.<sup>5,6</sup> It is well established that AKI is a major driver for CKD and is associated with noncommunicable diseases (NCDs), yet it receives little attention compared with other conditions.<sup>7</sup> Similarly, awareness of CKD is low despite CKD being common and expensive as well as increasing the risk of adverse events in people with other NCDs.<sup>7</sup> As such, effective leadership and governance, as components of health care systems, are essential across countries to ensure these conditions receive adequate national and international priority. The extent and impact of the various leadership and governance structures (policies, guidelines, and frameworks) for AKI and CKD across countries remains unclear.

As part of the Global Kidney Health Atlas (GKHA) project, a multinational survey conducted through the International Society of Nephrology (ISN),<sup>8,9</sup> we set out to understand the distribution of leadership and governance structures for kidney care worldwide. Furthermore, we sought to describe the modes of operation, specifically focusing on priority actions, advocacy efforts, strategies, guidelines, awareness, and barriers.

## RESULTS

In total, 125 of 130 countries (96%) that received an invitation participated in the survey. Of these, 93% ( $n = 116$ ) responded to the questions relevant to leadership and governance. Complete details on the response rate and population coverage of the survey have been published elsewhere.<sup>8,9</sup>

### Priority of and advocacy for kidney care

CKD was recognized as a health care priority (defined as outlining principles, defining practices, or both<sup>10</sup>) by government in 36% ( $n = 42$ ) of countries overall, and in 53% (9 of 17), 52% (16 of 31), 20% (6 of 30), and 29% (11 of 38) of low-, lower middle-, upper middle-, and high-income countries, respectively (Table 1). Overall, 42% (49 of 116) reported the existence of an advocacy group at higher levels of government to raise the profile of CKD and its prevention. This was more common in low- (53%; 9 of 17) and lower middle- (48%; 15 of 31) income countries compared with upper middle- (37%; 11 of 30) and high- (37%; 14 of 38)

income countries (Table 1). Overall, 46% (49 of 116) had neither CKD identified as a government health care priority nor an advocacy group for CKD. Identifying CKD as a government health care priority was significantly associated with having an advocacy group for CKD ( $\chi^2 = 11.57$ ;  $P = 0.001$ ). Advocacy for AKI was less than one-half that for CKD (Table 1).

### Strategies for kidney care

Fifty-nine percent (68 of 116) of countries overall had a national NCD strategy, and 18% (21 of 116) reported having a strategy under development (Table 2). A higher proportion of high-income countries (26%; 10 of 38), compared with low-income countries (12%; 2 of 17), reported no NCD strategy.

In total, 44% (48 of 109) of countries reported a national strategy for improving the care of nondialysis CKD patients, 55% (57 of 104) for chronic dialysis patients, and 47% (47 of 100) for kidney transplantation patients (Table 2). Conversely, 40% (46 of 116) of countries reported no national strategy for CKD care (irrespective of nondialysis CKD, chronic dialysis, or transplant). In these countries, other initiatives that identified CKD as a health care priority included having strategies at a regional or state level, a national position paper on CKD (a document providing an overview of information and recommendations for kidney care, but not mandated by legislation), and incentives for identifying CKD and providing quality care to CKD patients (Figure 1).

Forty-nine percent of countries (57 of 116) reported at least 1 strategy for improving the identification of AKI (Figure 2). The most common strategies were having tools available (32%; 37 of 116) and increasing access to acute dialysis facilities (31%;  $n = 36$ ). Sixteen percent of countries (19 of 116) reported a national position paper on AKI identification and care (Figure 2). Position papers were more common in high- (24%; 9 of 38) and upper middle- (23%; 7 of 30) income countries compared with lower middle-income countries (10%; 3 of 31). No low-income (0%) countries reported a national position paper on AKI identification and care (Figure 2).

National or regional organizations, either physician- or patient-oriented, that provide financial resources for kidney care were much higher for CKD (53% of countries; 62 of 116) than AKI (23%; 27 of 116). The presence of CKD organizations was lower in low-income countries (29%; 5 of 17) compared with high-income countries (66%; 25 of 38), and likewise for AKI organizations (6%; 1 of 17 and 29%; 11 of 38, respectively).

### Awareness and adoption of guidelines for kidney care

Overall, access to management and referral guidelines was less common for AKI (53%; 61 of 116) than CKD (79%; 92 of 116) (Table 3). A lack of guidelines was more common among low-income countries than high-income countries, for both AKI and CKD. National guidelines for AKI and CKD were available in 7% (8 of 116) and 27% (31 of 116) of countries, respectively (Table 3). Access to international

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