

## 2019 GKHA REGIONAL SLIDES PRESENTATIONS

### NORTH AMERICA & THE CARIBBEAN

#### SLIDE 1:

<opening slide>

#### SLIDE 2:

- Overview of presentation
  - Aim of GKHA
  - Methods (desk research and survey)
  - Key Results
  - Summary and implications

#### SLIDE 3:

- The impetus for the Atlas project came from the fact that we don't have any consolidated reliable data on the current status of kidney care either globally or regionally. In order to improve kidney care worldwide, we need to document where we are and where we need to go to monitor and motivate change.
- The vision of the Atlas is to achieve optimal and equitable kidney care worldwide. To accomplish this, we need to identify and close gaps related to the capacity or equity of kidney care. Hence, the GKHA serves to collect data using standardized indicators that measure kidney care delivery to provide evidence-based recommendations to relevant stakeholders.
- Overall, the goal of the GKHA is to improve the understanding of inter- and intra-national variability across the globe with respect to capacity for kidney care delivery. Through assessing and documenting capacity for kidney care across all world regions, we can work toward improving the quality and equity of kidney care worldwide.



#### SLIDE 4:

- To achieve this mission, the strategy of the GKHA is to collect data using standardized indicators that measure kidney care delivery to provide evidence-based recommendations to relevant stakeholders.
- First in 2016, the ISN conducted the first-ever survey to document the baseline capacity of kidney care. This allowed for the establishment of benchmarks overall, within ISN regions, and by World Bank income group. This was an important first step to understand where we are globally, with respect to the capacity and equity of kidney care delivery.
- The survey was repeated again in 2018 and will be every 4 years moving forward to monitor progress so we can work toward improving the areas needing change.
- Today's discussion will focus on the 2018 results, which were published in the 2019 Atlas.

#### SLIDE 5:

- Two key methods were used to produce the atlas: a desk research component, which involved searching literature and other data sources to calculate estimates; and a key opinion leader survey, whereby three leaders from each country (a nephrology society leader, a leader of a consumer representative organization, and a policymaker) submitted details on national kidney care capacity and practices with a specific focus on kidney disease.
- The online questionnaire was completed in July-September 2018. Stakeholders from 182 countries were invited to participate.
- Approximately 3 stakeholders from each country completed the survey. Any discrepancies within a country were resolved through follow-up meetings with regional and country leaders.

#### SLIDE 6:

- The survey followed a framework developed by the World Health Organization on health systems evaluation.
- This framework was released in 2010, which was a handbook of indicators and measurement strategies to monitor the building blocks of a health system. The WHO recognized that information is needed to track how health systems respond to increased inputs and improved processes, and the impact they have on improved health indicators. Therefore, a set of core indicators of health system performance was established, along with sustainable measurement strategies, to generate the required data.



- The framework considers health systems in terms of six core components or “building blocks”:
  - Service delivery;
  - Health workforce;
  - Health information systems;
  - Access to essential medicines;
  - Financing; and
  - Leadership/governance
- Through addressing each of these domains, the overall goals of the WHO strategy are to improve health (level and equity), health system responsiveness, protect social and financial risk, and improve efficiency.
- The GKHA models this framework to similarly aim to achieve these objectives, specific to kidney care.

#### SLIDE 7:

- The 2019 survey received input from 160 of the 182 invited countries, equaling a response rate of 88%.
- This covered nearly 99% of the world’s population.
- An additional 36 countries participated in the 2019 survey compared to the 2017 survey.

#### SLIDE 8:

- The GKHA reports overall global results for each indicator, and as well separates the data by ISN region and income group.
- Therefore, we are able to examine the level of variability across income levels and geographical regions.
- Knowing if there is variation between countries, either within a common ISN region or income group, is helpful when trying to promote equity of care.

#### SLIDE 9:

- This talk focuses on the region of North America and the Caribbean.
- There are 14 countries in the region: 3 are upper-middle and 11 are high income.

#### SLIDE 10:

- At the time of the survey, there were 370,499,303 people living in the 14 countries in North America and the Caribbean. The average country population was 136,244.
- The median GDP was 5 billion
- On average, 6% of the GDP was spent on healthcare (i.e., total health expenditure)

#### SLIDE 11:

- Just under 12% (11.46%) of the population in North America and the Caribbean has CKD, slightly over the global average of 10%.
- The Bahamas had the lowest prevalence at 9.93% and the Virgin Islands had the highest with 14.44%.
- Four per cent (3.68%) of all deaths in the region are attributed to CKD. Antigua and Barbuda had the highest rate with 4.61%.
- Nearly a quarter of the population has obesity (24.4%) and increased blood pressure (23.3%). The United States had the highest rate of obesity (37.3%) and St. Lucia had the highest rate of hypertension (27.1%).
- On average, 8% of the population smokes.

#### SLIDE 12:

- Data availability on the burden of end stage kidney disease is low in NAC.
- Only 2 countries have data on the incidence of transplantation or dialysis and 7 on the prevalence. Of these 7 countries, the median prevalence is 682.5 people receiving KRT per million population.
- 8 countries have prevalence data for chronic HD and PD. Of these, the median prevalence, respectively, is 821.3 pmp and 26.95 pmp.
- Turks and Caicos had the highest prevalence of chronic HD (1882.4 pmp) followed by the United States (1416.07 pmp). Jamaica had the lowest (192.7 pmp).
- Canada had the highest prevalence of chronic PD (161.1 pmp).
- Three countries (Barbados, Cayman Islands, and Turks and Caicos Islands) had a prevalence of 0 people receiving PD per million population.

#### SLIDE 13:

- Data on kidney transplantation in NAC is very low.



- Only 5/14 (36%) countries (Bahamas, Barbados, Canada, Jamaica, and the United States) have data available on the overall prevalence of kidney transplantation.
- Of the 5 countries with data, the median prevalence of kidney transplantation is 7%.
- Information on the source of kidney donation was only available in 2 countries (Canada and the United States).
- Of these, both had a higher prevalence of deceased donation (average 40.59 pmp) compared to live donation (15.41 pmp).

#### SLIDE 14:

- Annual costs of kidney replacement therapy were estimated, data were only available for 2 countries (Canada and the United States).
- Costs of dialysis were slightly higher in the United States (USD 88,395 for HD and USD 68,139 for PD) compared to Canada (USD 73,789 for HD and 44,434 for PD).
- However, the cost for the first year of kidney transplantation was higher in Canada (USD 82,852) compared to the United States (USD 35,325).
- In Canada, the HD/PD cost ratio was slightly higher (1.66) compared to the US (1.3), suggesting that HD delivery might be slightly more costly to deliver than PD, relative to the US.

#### SLIDE 15:

- Responses were received from 10 of 14 countries in NAC (71.4%) representing 99% of the region's population.

#### SLIDE 16:

- Scorecards were created for each country so they could compare results with other countries in the same area as well as between the first survey in 2017 and the follow-up two years later in 2019.
- Green represents availability, red represents not available and grey represents unknown or not applicable if they didn't complete a survey that year.
- Hemodialysis was available in all countries in NAC.
- Nearly 80% (7/9) countries provide chronic peritoneal dialysis services; Antigua and Barbuda and St. Lucia do not (no response from the Bahamas).
- Only 5 countries (Antigua & Barbuda, Canada, Jamaica, Trinidad & Tobago, and the United States) have kidney transplantation services available.



- Only one country (Antigua & Barbuda) funds medications for dialysis patients and only 3 (Antigua & Barbuda, Canada, and Trinidad & Tobago) fund medications for transplantation patients.
- Advocacy for CKD and ESKD was moderately high in the region. Only 3 countries do not have an advocacy group for CKD (Cayman Islands, St. Vincent & the Grenadines, and Trinidad & Tobago) or ESKD (Canada, St Lucia, Trinidad & Tobago).
- No countries reported an advocacy group for AKI.

#### SLIDE 17:

- 3 countries in NAC reported that non-dialysis CKD care was funded by the government: 2 exclusively (Canada and Jamaica) and 1 (St. Vincent and the Grenadines) with some fees at the point of care.
- One country (St. Kitts and Nevis) reported that care was exclusively private and out-of-pocket for patients.
- 6 reported a mix of public and private sources.

#### SLIDE 18:

- Two countries in NAC (Antigua and Barbuda and Canada) reported that kidney replacement therapy was exclusively funded by the government.
- One (St Kitts and Nevis) reported that KRT was exclusively covered out-of-pocket by patients.
- 7 reported that KRT costs were covered through a mix of public and private sources.

#### SLIDE 19:

- 8/9 (89% [no response from the Bahamas]) of countries in NAC reported that nephrologists are primarily responsible for people with ESKD.
- Other healthcare providers share the responsibility in other countries, for example 2 countries (Jamaica and St. Kitts and Nevis) reported that primary care physicians are also responsible for ESKD care and 2 (Jamaica and Trinidad and Tobago) reported that nurses share the responsibility.
- Only 3 countries in NAC (Jamaica, St. Lucia, and the United States) reported that multidisciplinary teams are utilized to care for people with ESKD.

#### SLIDE 20:

- Workforce shortages, highlighted in red, were moderately reported in NAC.
- Four countries in the region (Cayman Islands, Jamaica, St. Kitts and Nevis, and the United States) reported shortages of nephrologists.
- No workforce limitations of any kind were reported in the Bahamas or Canada.

#### SLIDE 21:

- In NAC, the density of nephrologists was 18.13 nephrologists per million population, which was much higher than the worldwide average of 9.95 pmp.
- Countries in NAC with the lowest densities were: Jamaica (4.27 pmp) and Trinidad and Tobago (5.76 pmp). Countries with the highest were: Antigua and Barbuda (31.29 pmp), United States (29.54 pmp), and St. Vincent and the Grenadines (29.46 pmp).
- Despite a high density of nephrologists, nephrology trainee density was much lower in the region. The global median density of trainees is 1.4 per million population. In NAC, 8 countries provided data on the number of trainees, 5 of which were 0. Of the 3 countries that have at least one trainee (Canada, St. Kitts and Nevis, and the United States) the median was 1.74 trainees pmp.

#### SLIDE 22:

- Respondents were asked to report the number of centres that provide chronic hemodialysis in their country. All countries in NAC reported that chronic HD services were available.
- Globally, the median density was 4.5 centers per million population. In NAC, the density was 18.13 pmp.
- Countries with the highest densities were: Cayman Islands (33.55 pmp), the United States (20.54 pmp), and St. Vincent and the Grenadines (19.64 pmp).
- Countries with the lowest densities were: Jamaica (4.62 pmp), Canada (5.57 pmp), and Antigua and Barbuda (10.43 pmp).

#### SLIDE 23:

- Respondents were also asked to report the number of centres that provide chronic peritoneal dialysis in their country. In NAC, 7 of 10 countries reported that chronic PD was available. This is similar slightly lower than the global average, which indicated that 81% of countries worldwide offer PD.
- The global median density of PD centers per million population was 1.3 centers pmp. In NAC, the density was 7.16 pmp.

- Countries with the highest densities were: St. Kitts and Nevis (18.83 pmp), Cayman Islands (16.77 pmp), St. Vincent and the Grenadines (9.82 pmp)
- Countries with the lowest densities were: Jamaica (1.07 pmp), Canada (1.39 pmp), and Trinidad and Tobago (1.65 pmp).

#### SLIDE 24:

- Respondents were also asked to report the number of centres that provide kidney transplantation in their country. In NAC, 5 countries (50%) reported that kidney transplantation was available. This is lower than the global average, which indicated that 74% of countries worldwide offer kidney transplantation.
- Globally, among the countries with kidney transplantation services, the average is 0.4 centres pmp. In NAC, the median density was 0.75 pmp.
- Of the 5 countries with transplantation services, Antigua and Barbuda had the highest density (10.43 centres pmp) and Jamaica had the lowest at 0.36 pmp.

#### SLIDE 25:

- Of the 5 countries in NAC that offer kidney transplantation services, 2 (Antigua and Barbuda and Jamaica) rely on live donation only, the rest use a combination of live and deceased organ donation.
- Two countries use a national waitlist, one uses a regional list only, and 2 have no wait list for transplantation.

#### SLIDE 26:

- While all countries in NAC reported that chronic HD was available, the quality of these services varied.
- Only 5 (50%) countries in the region have a center-based service that involves treatment 3x week for 3-4 hours. This is much less than the global average, which reported that 77% of countries offer adequate frequency for HD services.
- Only 4 of the 7 countries in NAC with PD services available reported an ability to do adequate exchanges 3-4x day (or equivalent cycles on automated PD). This is equal to the global average of 58% of countries that offer adequate PD exchange.

#### SLIDE 27:

- Home hemodialysis was not common in this region.



- Only 2 countries (Canada and the United States) have services generally available, which means that at least half of renal centres provide patients with home hemodialysis training.
- One country (Cayman Islands) reported that home hemodialysis is available, but not generally available to most patients.
- Six countries reported that home hemodialysis is never available.

#### SLIDE 28:

- Conservative kidney management is a treatment option for ESKD, which does not include dialysis or transplantation.
- There are 2 types of conservative kidney management: choice-restricted or medically advised. Choice-restricted means that patients opt for CKM due to limitations in resources, whereas medically advised, or chosen, is a deliberate choice of CKM as it is likely the better treatment option for an individual rather than KRT.
- Six of the 10 countries in NAC reported that CKM was available (Canada, Cayman Islands, Jamaica, St. Lucia, St. Vincent and the Grenadines, and the United States).

#### SLIDE 29:

- Few countries in NAC have a registry for any level of kidney disease.
- No countries have a CKD or AKI registry.
- Four countries have a registry for dialysis (Canada, Jamaica, St. Lucia, and the United States).
- Three countries have a registry for kidney transplantation (Canada, Trinidad and Tobago, and the United States).

#### SLIDE 30:

In summary, the 2019 GKHA highlights several important findings for North America and the Caribbean.

*Availability, access, and quality of dialysis is high, transplantation services limited*

- HD was available in all countries in NAC and 80% of countries offer chronic PD services.

- Only 5 countries have transplantation available.
- While all countries offer chronic HD, access to care and quality of treatment was limited. Center-based hemodialysis service that involves treatment 3x week for 3-4 hours was only generally available in half of countries in the region.
- Home hemodialysis is generally available in only 2 countries in NAC (Canada and the United States) and is never available in 60% of countries.
- Of the 8 countries in NAC that offer PD, only half reported an ability to do adequate exchanges 3-4x day.
- Of the countries in NAC that offer transplantation services, information on donor type and waitlists are limited.

*Conservative kidney management is available, generally as chosen or medically advised*

- 60% of countries in NAC reported that CKM was available.
- This was less than the overall global score (80%).
- Of these 6 countries, all reported that chosen or medically advised CKM was generally available.

*Government funding for kidney care is low*

- Few countries cover all treatment costs for KRT. Only one country (Antigua & Barbuda) funds medications for dialysis patients and only 3 (Antigua & Barbuda, Canada, and Trinidad & Tobago) fund medications for transplantation patients.
- Similarly, government funding for CKD care was limited. 3 countries in NAC reported that non-dialysis CKD care was funded by the government: 2 exclusively (Canada and Jamaica) and 1 (St. Vincent and the Grenadines) with some fees at the point of care.
- Two countries in NAC (Antigua and Barbuda and Canada) reported that kidney replacement therapy was exclusively funded by the government.

*Few registries across all levels of kidney disease, particularly for CKD and AKI*

- No countries in NAC have a registry for non-dialysis CKD or AKI.
- 40% (4/10) have a registry for dialysis and 30% have one for transplantation.

*High workforce capacity: high nephrologist density, few provider shortages reported.*

*Half of countries with no nephrology trainees*

- The nephrologist density of NAC (18.13 pmp) was larger than the overall (9.10 pmp).
- Nephrology trainee density; however, was much lower in the region.
- While the median of trainees in NAC was 0 trainees pmp, compared to the global score of 1.4 pmp. This is likely due to the fact that 5 countries reported 0 trainees.

- Of the 3 countries in the region that reported at least one trainee (Canada, St. Kitts & Nevis, and the United States), the median average of trainees pmp was 1.74.
- Workforce limitations were not commonly reported in NAC, relative to the global score. 40% (4/10) reported a shortage of nephrologists.
- Only 3 (30%) reported a shortage of dialysis nurses and few other allied health professional shortages were reported.
- Increasing the workforce capacity through other providers such as nurses, pharmacists, dietitians, may help alleviate some of the limitations. Further, providing primary care physicians with accessible guidelines on how to prevent and treat kidney disease is important.

*Strong advocacy for CKD and ESKD, none for AKI*

- In NAC, advocacy groups were common for CKD and ESKD but non-existent for AKI.
- 70% of countries in NAC have advocacy groups for CKD and ESKD.
- No countries in the region reported an advocacy group for AKI.
- Increasing the awareness of kidney disease in the public domain, as well as with other nonprofits devoted to global health, may help promote prioritization of kidney disease.
- Highlighting the gaps of care, with respect to quality and equity, coupled with the burden and consequences of untreated ESKD may help improve advocacy.

SLIDE 31:

There are important implications to consider. Based on these survey findings, key recommendations to drive future activities for optimizing kidney care globally are proposed:

*Increase health care financing for ESKD prevention and management*

- While resource limitations are an obvious barrier, focusing on preventing ESKD through appropriate hypertension and diabetes management may be more cost-effective overall. Government funding to cover medication costs may allow more patients to treat earlier stage CKD, thereby preventing the need for more costly ESKD treatment and the obvious burden this has on patients' wellbeing.

*Address workforce shortages through multidisciplinary teams and telemedicine*

- Shortages of nephrologists, surgeons, dialysis nurses, and other key allied health professionals were noted across most countries. Similarly simply producing more



nephrologists may not be feasible or appropriate, and sharing the workload across multiple providers will not only promote the use of multidisciplinary teams but further, allow for more and better care delivery across more patients. Telemedicine may help particularly in addressing gaps in care among rural patients, and enhancing capacity through training programs such as ISN Fellowship, visiting ambassador programs, etc.

*Incorporate the collection and reporting of quality indicators in ESKD care*

- Measuring and reporting on key quality indicators is an important driver in healthcare improvement. Ensuring facilities are supported with information systems that allow for the systematic measurement and reporting of indicators is a first key step to increasing the rate of monitoring among countries. Further, understanding if or how the collection and reporting of indicators are being used to improve care is needed.

*Expand health information systems to prevent and manage ESKD*

- Similarly, good quality HIS are vital for kidney disease management within a country. A lack of data on disease prevalence, incidence, resource use, and quality of care limits government and provider ability to monitor and evaluate the care provided as well as predicts appropriate resource allocation so that sufficient facilities, medicines, and healthcare professionals are trained and available.

*Promote ESKD prevention and treatment by implementing policies, strategies, and advocacy, and mitigating barriers*

- Lastly, policies and strategies are important for consistent approaches within a country for optimal care delivery, as well as for accountability, leadership, and knowledge exchange. Advocacy may help promote the increase of government prioritization and further, public awareness of how to prevent and manage kidney disease. Without acknowledging and mitigating barriers, it would be a challenge to achieve of successes out of these recommendations. Competing priorities and needs (for example, clean water supply and basic sanitation, maternal and child health, malnutrition, etc.) represent formidable barriers that can limit implementation of the recommended strategies in the region.

SLIDE 32:

- Each Atlas report is available for free download at the ISN webpage.
- To download a copy, please visit the ISN webpage.